Living in the Skin That I Am: An Organizational Autoethnography of an Adult Educator's Plight to Survive the Stigma of Invisible and Episodic Disability in an Academy of Administrivia

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Submitted in partial fulfillment of

the requirements for the degree of

Master of Education

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Abstract

Through the reflective lens of an adult educator with invisible and episodic disabilities, this paper has been written as an organizational autoethnography. Through a process of autoethnographical sensemaking, it is intended to illuminate important gaps in organizational theory. Feminist/relational care ethics, critical reflection, and transformative learning serve as the educational theories that comprise its framework. In telling my story, embodied writing and performance narrative are used to convey the felt existence of a body exposed through words—where my "abled" and "disabled" professional teaching and learning identities may be studied against the backdrop of organizational policies and procedures. Words used to describe unfamiliar experiences and situations shape meaning for which new meaning may emerge. At the conclusion of this paper, an alternative frame of reference—a view from the margins—may be offered to articulate authenticity in the expectancy of workplace equity for adult educators with disabilities. Taken collectively on a larger level, it is hoped that this research may provide a source of inspiration for systemic organizational change in adult learning environments.

Acknowledgements

Writing this paper would not have been possible without the loving support of my family—my husband Steven, two children Timothy and Benjamin, and my best friend Jules. For allowing me into their hearts and private worlds through story, I thank them.

For the unwavering support and love that I felt from my supervisor, Hilary Brown, I thank her. Through writing she has helped me reclaim my voice and recognize the joy of being an embodied human.

For Thomas Busnarda, who first introduced me to the feminist voice through the works of Carol Gilligan and Nel Noddings, I thank him.

For my parents, my brother Rob, my little niece, my sister Kate, and my cousins Robin and Agnes—who held me and raised me in a foundation of care and compassion, I thank them.

For those who made themselves vulnerable—Maureen, Maggie, Janis, Patti, Izzy, Theresa, Sandi, Janice, Michael, Cynthia, and Jean—by allowing me into their world so that I could better understand the source of my pain and my struggle, I thank them. They inspired me with strength, wisdom, passion, and compassion to overcome personal challenges that seemed like insurmountable obstacles during a time in which I felt scared, frightened, and confused—during time when my body and identity were changing.

For the words and wisdom of Jean Vanier, Arthur Frank, Tami Spry, Kathy Charmaz, Carol Gilligan, and Nel Noddings, I thank them, for they have taught me to see life and myself differently.

For all that have touched my life and helped me to reflect about the person I once was, who I am now—and who I am learning to become, I thank them. For I stumbled along a path of self-discovery and am learning to feel more comfortable in the skin that I have been given to live in through the role and the purpose for which I have been created.

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CHAPTER ONE: SETTING THE STAGE

> Marginalization means boundaries or barriers, distance or separation, and division or difference. Disconnection, devaluation, discrimination, and deprivation exemplify experiences of marginalization. Views from the margins reflect these characteristics and subsequent experiences reconfirm them. A view from the margins may emanate from difference; it may also offer significant differences in knowledge, meanings, and priorities - a distinctive view, another course of action. A view from the margins can illuminate another way of being in the world and, taken collectively, a source of institutional change. (Charmaz, 2008, pp. 9-10)

Rutted against the backdrop of organizational "administrivia", this research is a self-study—presented as an organizational autoethnography—of my lived experiences while working in a university health-care setting as an adult educator with "invisible" and episodic health conditions. It chronicles my pilgrimage—my plight, to make sense of my experiences with stigma and disability discrimination during my employ at the university. While constricted in a disability paradigm of organizational policies and procedures, my "abled" and "disabled" professional teaching and learning identities are studied. Notes, curriculum assignments, and transcripts I generated and collected during that time serve as reflective insight to supplement layered accounts of written narratives—my experiences—that have been storied, re-storied, and analyzed retrospectively.

Drawing on the techniques of embodied writing and performance narrative, this research is intended to "connect the micro and everyday mundane aspects of organizational life with the broader political and strategic organizational agendas and practices" (Boyle & Parry, 2007, p. 186); it serves as the stage that enables me to interpret and make sense of my experiences "from the inside out … entwining in words sense with the sense of the world" (Anderson, 2001, p. 84).

As a powerful tool to "fill important gaps in organizational theory" (Weick, Sutcliffe, & Obstfeld, 2005, p. 409), embodied writing uses words to convey the human experience of emotion, feeling, action, and inaction. Weick et al. (2005) further describe how embodied writing is used as an instrument to facilitate organizational change by stating:

> Turning circumstances into a situation that is comprehended explicitly in words and that serves as a springboard into action … [and to] unfold as a sequence in which people concerned with identity in the social context of other actors engage ongoing circumstances for which they extract cues and make plausible sense retrospectively. (p. 409)

From an organizational context, words used to describe unfamiliar experiences and situations shape meaning for which new meaning may emerge. New meaning perspectives—organizational learning—may be evidenced in changed policies and procedures. In their critique of organizational sensemaking, Gioia et al. (as cited in Weick et al.,2005) highlight the use of narrative as both process and product of organizational change. Specifically they stated,

> First, sensemaking occurs when a flow of organizational circumstances is turned into words and salient categories. Second, organizing itself is embodied in written and spoken texts. Third, reading, writing, con versing, and editing are crucial actions that serve as the media through which the invisible hand of institutions shapes conduct. (409)

At the conclusion of this project, "through the lived experience of the body portrayed in words" (Anderson, 2001, p. 83) this paper will offer an alternative frame of reference, a "view from the margins" (Charmaz, 2008, pp. 9-10) that articulates authenticity in the expectancy of workplace equity for adult educators with disabilities. Taken collectively on a larger level, it is hoped that this research may provide a source of inspiration for systemic organizational change in adult learning environments.

Contextualizing the Quest

> Cultural perceptions of disability do not emerge in a vacuum; they accrue slowly and over time, informed by normalizing discourses in medicine and psychology and reinforced by institutions and unchallenged beliefs of deficiency and need …. With the medical lens fixed on the individual and his or her disability, the larger political, economic, and material forces at play in an able-ist society fall somewhere outside the frame. (Ware, 2001, p. 107)

There is a paucity of literature that captures and discusses the teaching and learning experiences of adult educators who live the paradigm of invisible and/or episodic disability in the context of adult education and adult learning environments.

According to Clark (2006), many adult education scholars have overlooked the possibility of exploring disability as a social category of investigation within an interdisciplinary adult education framework (p. 309). Specifically she recognized that

> Disability studies is an emerging field of inquiry that investigates the disability experience as a socially constructed phenomenon … the literature of adult education shows that we are not making these same connections. Nor are we conducting a thorough investigation of how the manifestations of the disability experience may affect and/or constrain the adult learning context. (p. 308)

In describing the social constructionist view of illness Conrad and Barker (2010) stated, "In contrast to the medical model, which assumes that diseases are universal and invariant to time or place, social constructionists emphasize how the meaning and experience of illness is shaped by cultural and social systems" (p. 308). Just as Clark recognized the deficiency in current adult education theory—for its failure to consider illness/disability within the power balance of cultural and social systems, Rocco (2011) acknowledged that this gap in educational inquiry exists because "disability is rarely understood in adult education as a socially constructed category or as an identity marker used to oppress and categorize" (p. 97). He reasoned that "disability is still viewed from a technical rational perspective … while the social construction of race, gender, and sexual orientation is a frequent theme in adult education" (p. 98). To further the evolution of educational philosophy and practice, disability—as a bodily and socially constructed experience—is important to

understand in the context of adult education theories. Documenting and examining the disability experience through an adult education lens will further the evolution and construction of culturally diverse knowledge perspectives.

Avowal of the Quest's Query

Current literature regarding stigma and disability discrimination in adult education work environments underscores the experiential perceptions and lived experiences of adult educators with invisible and/or episodic disabilities. Little is known about the, "tacit and subaltern aspects of organization – such as how actions which lead to negative or positive organizational outcomes actually play out" (Parry & Boyle, 2009, p. 695) in the context of disability rights and power issues in adult education and in adult education work settings.

Meaning Behind the Mission

Highlighted in an adult education workplace setting and voiced through the experience of an adult educator with invisible and episodic disabilities, the purpose of this study is threefold:

1. to make sense of my experiences with stigma and disability discrimination;
2. to contribute to the body of literature that embodies the lived experience of stigma and disability discrimination and;
3. to inspire change in the development of inclusive work practices for persons with invisible and/or episodic disabilities.

Voicing the Query

To address the broad conceptual aspects of disability rights in relation to power issues in adult education and in adult education work environments, the questions this study specifically asks are as follows:

1. As a professional adult educator, what is my story of identity transformation in relation to experiences of stigma and disability discrimination in an adult education workplace?
2. How does my "abled" and "disabled" body evoke literary reverence in the sensemaking process and lived experience of stigma and disability? discrimination within a workplace culture of organizational administrivia?
3. How have my experiences –moving through the paradigm of disability— shaped my role as an educator within the framework of adult education?

Inspiration for Movement

The literature that captures and discusses the teaching and learning experiences of adult educators with invisible and/or episodic disability in the context of adult education and adult education work settings is scarce (Clark, 2006; Rocco, 2011; Ross-Gordon, 2002). From a policy development perspective, the World Health Organization (2011) recognized that, "in formulating and implementing policies, laws, and services, people with disabilities should be consulted and actively involved" (p. 18). The reality, however, for many adults living with stigmatizing invisible and/or episodic disabilities, is that they exist on the margins of society, classified as "vulnerable," and are often discouraged from societal participation

(Clair, Beatty & MacLean, 2005; Conrad et al., 2010; Davis, 2005; Fullick, 2008; McDonald & Keys, 2008; Reidpath, Chan, Gifford, & Allotey, 2005; Rocco, 2011; Wooten & James, 2005). Townsend (as cited in Jongbloed, 2003) stated that "the way in which an issue is viewed contains an implicit prescription for policy" (p. 203). Following this logic, it therefore reasons that the way in which disability experiences are framed and subsequently examined in the context of the workplace and adult learning environments is imperative for the development of socially inclusive organizational policies and workplace practices.

For those living the experience of invisible and/or episodic disability, this research will serve as an important teaching and learning tool in the development of educational strategies for improved adult education workplace practices. Written narratives are intended to illustrate a collage of transitory scenes—like a sequence of still frames—tracing the learning process of an "abled" and "disabled" adult educator in search of a "new" identity in response to experiences of stigma and disability discrimination. For adult education and workplace administrators, this paper is intended to facilitate the creation of a "new type" of organizational knowing— through the performance and interpretation of autoethnographic narrative—so that persons with invisible and/or episodic disabilities may be corporeally included in the society of healthy workplace living.

Theoretical Framework

The frameworks underpinning this study are rooted in the academic theories of: (a) feminist and relational care ethics, (b) critical reflection, and (c) transformative learning.

Living with invisible and episodic disabilities, my perception of self-identity change in response to experiences of stigma and disability discrimination in the workplace is illustrated—as a transformative learning experience—through writing and visual arts. By way of living and reliving stories through their narration, differences in the perception of human experiences—my experiences in relation to others'—challenged me to engage in critical reflection. By "examining the validity . . . [and] assessing the truth or justification of taken for granted concepts" (Mezirow, 1998, p. 192), I was able to gain deeper insight into the underlying assumptions, beliefs, and values I held. In the final conception of my autoethnographic kaleidoscope, narrative analysis comprises: (a) experiences with self and others, (b) continuity of experiences to past, present, and future, and (c) situational backdrop in relation to how I view myself and the world around me.

Scope and Limitations of the Study

> Researchers do not exist in isolation. We live connected to social networks that include friends and relatives, partners and children, co-workers and students, and we work in universities and research facilities. Consequently, when we conduct and write research, we implicate others in our work …. These "relational ethics" are heightened for autoethnographers. In using personal

> experience, autoethnographers not only implicate themselves with their work, but also close, intimate others. (Ellis, Adams, & Bochner, 2011, para 29)

The scope and limitations of this inquiry are bound by: (a) my perceptions and interpretations of personal experience and (b) "relational concerns throughout the research and writing process" of autoethnography (Ellis et al., 2011, para. 28). Perception and interpretation of personal experiences are influenced by my ability to make sense of those experiences. In a paper that discusses the process of sensemaking, the authors summarized its distinctive features—all of which influence an autoethnographer's perception and interpretation of experience. They stated that the common traits of sensemaking include:

> Its genesis in disruptive ambiguity, its beginnings in acts of noticing and bracketing, its mixture of retrospect and prospect, its reliance on presumptions to guide action, its embedding in interdependence, and its culmination in articulation …. Answers to the question "what's the story?" emerge from retrospect, connections with past experience, and dialogue among people who act on behalf of larger social units. Answers to the question "now what?" emerge from presumptions about the future, articulation concurrent with action, and projects that become increasingly clear as they unfold. (Weick et al., 2005 p. 413)

By knowing, beforehand, the limitations of autoethnographic work and the difficulties that autoethnographers experience in the process of their research, writing, and analysis, it is anticipated that the results of this organizational

autoethnography will carry credibility in relation to the wider cultural, political, and social meanings than research that does not include vigourous critical self-reflective processes.

Outline of Remainder of the Document

The subsequent four chapters of this paper will comprise the following: Chapter Two—a review of the literature related to feminist ethics, identity change, and transformative learning; Chapter Three—the methodology behind this study and its research design; Chapter Four—performative stories as both "data" and "results"; Chapter Five—a summary of findings, discussion about the implication of findings, and recommendations for future areas of inquiry.

CHAPTER TWO: A LITERATURE REHEARSAL

> Care theory, in contrast to classical liberalism, recognizes that we are not cast into the world as rational choice-makers. We are, rather, all born as helpless, totally vulnerable beings in need of others. This starting point informs care theory, which is fundamentally relational …. Care theory emphasizes caring as an attribute of certain relations. The relation is ontologically basic; the individual moral agent is not the sole focus of ethical interest. Care theorists acknowledge the virtue sense of "caring," but we are more deeply concerned with the relational sense. In that context, we ascribe the contributions of both carer and cared-for to the caring relation. (Noddings, 2002, pp. 441-442)

Voice as Instrument of Care

Although the feminist voice has evolved over the course of many years, in the early 1980s, through their work, "The Contribution of Women's Thoughts to the Development Theory" (Gilligan, 1982), and "Caring: A feminine approach to ethics and moral education" (Noddings, 1984), Gilligan and Noddings pioneered a revolutionary school of thought in the understanding of moral development theory. Unlike Kolberg's prevailing theory of moral development that was based on an ethics of justice and hierarchal rules that exemplified a traditional "masculine" way of thinking, Gilligan and Noddings recognized the importance of relational dynamics.

They founded this "new" way of thinking about moral development theory and based it on an ethics of care and relational inclusiveness.

In an attempt to understand the differences that existed between the ethical decision making processes between men and women, Carol Gilligan noted that Kohlberg's theory of moral development failed to provide an equitable framework for the embodiment of the "female" voice (Gilligan, 1982, p. 1). In light of this deficiency, Gilligan sought to unearth this missing element in order to allow a fair account of the ethical views and experiences of both sexes (Gilligan, 1982, p. 1). By including the female voice in her research, Gilligan expanded the theory of moral development, thus creating a paradigm shift. She identified that "the morality of response and care and the connected self, calls attention to the reality of interdependence in the lives of all human beings" (Gilligan, 1982, p. 30). Gilligan further clarified these findings and stated that

> The story of moral development told through a focus of care and responsiveness is a story of continuing connection, first a story of connection between parent and child, then a story of connection between all human beings. In place of the image of hierarchy, we find the image of a network, conveying a different vision of connection, a different perception of the relationship between others and self … [and] a responsiveness that requires a kind of vigilance to perceiving the particular needs of others in terms of their own particular situations and life histories, a responsiveness that reflects a moral ideal of care, where everyone would be responded to and included, and no one would be left alone, or hurt. (Gilligan, 1982, p. 30)

This relational connection of self to others laid the foundation of feminist/relational care ethics—and recognition of different voices—those that may be silenced or heard according to the contextual balances of societal and cultural agendas.

Later, in an interview with Kiegelmann (2009), Gilligan described the concept of voice as an expression of human interconnection as she stated, "We are born with a voice and in relationship with the ability to communicate with other people …. Voice destabilizes the notion of separateness …. Voice is an instrument of relationship, and in losing voice, one loses relationship." (lines 61 & 66)

In this same vein of feminist thinking, through storytelling and story listening, Frank (1995) highlighted the importance of voice in the experience of illness and relational care. Specifically he stated,

> in story, the common bond of suffering joins bodies in their shared vulnerability … [and] as wounded, people may be cared for, but as storytellers, they care for others …. Because stories can heal, the wounded healer and the wounded storyteller are not separate, but are different aspects of the same figure." (pp. xi-xii)

Frank further describes the relational aspect of voice as both the process and instrum ent that ill persons use to claim their identity in the face of dominant medical discourse. He stated that

> Telling stories of illness is the attempt instigate by the body's disease, to give a voice to an experience that medicine cannot describe. This voice is embodied

> in a specific person, but is equally social; taking its speech from the postmodern time we live in. The voice of the ill person is made possible by modernist medicine, but it cannot be contained within modernist assumptions, particularly those about medical professional dominance and the narrative surrender this dominance requires. A divide has been crossed into new territory, the postern-modern, and we know this crossing by the new voices that are heard. (p. 18)

Expression of voice in the process of decision making and in the process of self-advocacy involves awareness, sensitivity, and access to resources that assist its articulation. Noddings (2010) stated that in order for caring to be effective, the care-giver must "respond appropriately to the expressed needs of the immediate cared-for while considering the likely effects of their decisions on the wider web of care and on the caring relation itself" (p.148). Noddings further added that the relational process of decision making in care ethics is made on the careful consideration and response to the needs of the vulnerable in relation to community, participation and the moral dimensions of the caring relationship itself. She explained:

> Care ethics demands a well-developed capacity for reasoning because it does not depend on axiomatic rules and principles. Carers must think well in order to assess and to respond appropriately to the expressed needs of the immediate cared-for while considering the likely effects of their decisions on the wider web of care and on the caring relation itself. Both reflective and instrumental

> reasoning are required. But feeling motivates our action and moral reasoning at every step. (p. 148)

A more contemporary interpretation of feminist ethics draws awareness to the established frameworks and activities that continue to cultivate patterns of unfairness and discrimination—so that silenced voices may be heard (Eckenwiler, Feinholz, Ells, & Schonfeld, 2008, p. 162). A feminist ethics of care transcends gender inequality; through the examination of relational dynamics that influence community participation for persons whose voices have been silenced, it extends the hand of humanity to all in need of care.

Self-Identity Change Performance

In the process of seeking care from family, friends, and health-care professionals, "sick people sometimes dare to talk about symptoms that seem less important [to physicians] … but they are not always given a proper hearing" (Godard, 2011, p. 291). The difficulty a person with invisible and/or episodic illness or disabilities may face when telling stories, however, is that physiologically, an ill or disabled person may be challenged to express voice. Waves of thoughts, feelings, and emotions during an illness experience may appear random and are often not experienced in a seemingly "logical" or "rational" sequences of accounts (Charmaz, 2008; Frank, 1995; Sakalys, 2003). Many "taken for granted" ways in which healthy persons use their body to express meaning may no longer be feasible for persons experiencing illness or disability—without the inclusive and dignified utilization of accommodative resources. This is particularly true when disability symptoms are

rare, episodic, and "invisible" in nature. In consideration of this struggle, Frank (1995) explained that

> People telling illness stories do not simply describe their sick bodies, their bodies give their stories their particular shape and direction. People certainly talk about their bodies in illness stories, what is harder to hear in the story is the body creating the person. (p. 27)

Stories of illness and disability experiences often express perceptions of self-identity change in context to interaction, continuity, and situation (Frank, 1995; Nettelbeck, 2008; Ollerenshaw & Cresswell, 2002). Learning to understand the constructs of one's identity—and one's changing identity—involves critical self-reflection and contextualization of meanings underlying the assumptions grounding one's beliefs, values, and feelings (Mezirow, 1990). As pre- and post-illness experiences are framed and reframed, through the deconstruction and reconstruction of self-concept—processes and experiences of self-identity occur—and transformative learning takes place (Barclay-Goddard, King, Dubouloz, & Schwartz, 2012).

For persons who live with chronic invisible and episodic disabilities, their identity change experiences take place on multiple levels—within their physical body, within their psychological constitution, and within their interpersonal relationships. For some, episodes of invisible and/or episodic disability trigger experiences of self and social identity perception changes—just as they may for persons who experience visible changes in health (Charmaz, 1983, 1995). Some

scholars suggest that self-identity perception change is linked to the self-concept development theory (Bailey, 200; Bandura, 1977; Epstien, 1973), where self-identity is defined as the "measurable concretes about what one does (e.g. achieving work products, like sports records), measurable aspects of how one appears (e.g. one's body proportions) and material things one has" (Bailey, 2003, p. 383). Bailey further suggested that "the assessments placed on these [self-concept] qualities may be significantly influenced by the outsiders in one's immediate environment and/or by society at large" (2003, p. 383). Society's reactions to and interpretations of a person's disabilities contribute in part to the transformation of that individual's self-concept (Conrad et al., 2010; Davison, Phennebaker, & Dickerson, 2000). Davison et al. (2000) explained that social interaction influences self-concept impacts and self-identity. Specifically they stated,

> Through interpersonal exchanges, patients develop an understanding of their illness: They may talk to friends, relatives, and professionals about what their diagnosis and treatment may entail …. Over the course of their particular illness, relationships are strained or broken, and new ones become valuable, such as those with doctors, nurses, or physical therapists. For some, the condition itself constitutes a dangerous secret that erects a barrier between themselves and their support network. Thus, patients' experiences of illness both influence, and are influenced by the social fabric that surrounds them. (p. 205)

Elaborating on this explanation, in his theory coined “the Looking Glass-Self”, Charles Horton Colley (as cited in Burbank & Martins, 2009) stated that person’s self-concept is based on the perceptions of self in relation to others and others’ perceptions of self. Colley stated that “the individual is able to view the self as object, to step outside and imagine viewing one’s self as others would” (Burbank et al., 2009, p. 28). Similarly, Charmaz (1995) described how the chronic illness experience shapes a person’s self-identity through reassessment of self—through critical reflection and through transformative learning. Charmaz stated,

> As chronic illness encroaches upon life, people learn that it erodes their taken-for-granted preferred identities as well as their health …. They may discover that visible illness and disability can leave them with a master status and overriding stigmatized identity. Because of their physical losses, they reassess who they are and who they can become …. They form identity goals as they try to reconstruct normal lives to whatever extent possible …. As they test their bodies and themselves, ill people need to make identity trade-offs at certain points, or even to lower their identity goals systematically until they match their lessened capacities. At other times, they may gradually raise their hopes and progressively increase their identity goals when they meet with success. Therefore, both raised or lowered identity goals form an implicit identity hierarchy that ill people create as they adapt to bodily loss and change. (p. 660)

Adapting to bodily loss and changing identity goals through the process of critical self-reflection is both product and process of transformative learning.

CHAPTER THREE: STAGECRAFT

Autoethnography is body and verse. It
is self and other and one and many.

It is ensemble, acapella, and accompaniment.
Autoethnography is place and space and
time. It is personal, political and palpable.

It is art and craft. It is jazz and blues.
It is messy, bloody and unruly.

It is agency, rendition and dialogue.
It is danger, trouble, and pain.

It is critical, reflexive, performative, and often forgiving.

It is the string theories of pain and privilege forever woven into fabrics of power/lessness.

It is skin/flings of melanin and bodies in the gendered hues of sanctuary and violence.

It is a subaltern narrative revealing the understory of hegemonic systems.
It is skeptical and restorative.

It is an interpreted body of evidence.
It is personally accountable.

It is wholly none of these, but fragments of each.

It is a performance of possibilities. (Spry, 2011, pp. 15—16)

Ellis et al. (2011) stated that "autoethnography is an approach to research and writing that seeks to describe and systematically analyze personal experience in order to understand cultural experience" (para. 1). And so, since the goal of this research is to capture and examine my experiences of stigma and discrimination as an adult educator with disabilities, in the performance of this composition, autoethnography will be used as both the method and results of data generation from which findings will be drawn. Reflection on the personal and professional relationships that connect self to organizational culture will be examined through an ethics of relational care (Gilligan, 1982; Noddings, 1984). Embodied writing that "drops the external witnessing perspective customary for conventional, 'objective' science … [and] speaks for itself through the vehicle of words … inside the body as it lives" (Anderson, 2001, p. 7) will be used to reveal the humanness of my experiences in story. Autoethnographic narratives will be analyzed using Clandinin and Connelley's (2000) metaphoric model of the three dimensional inquiries of narrative space in addition to Spry's model of performative autoethnography of body, paper, stage. Clandinin and Connelley define the three analytical spheres for narrative inquiry as "[1.] the personal and social (interaction) along one dimension; [2.] past, present and future (continuity) along a second dimension; [and 3.] place (situation) along a third dimension" (Clandinin, 2006, p. 47). Spry's (2011) model of performative autoethnography uses:

> [1.] body … will present the performative-I as the subjectivity of the researcher … [2.] paper … will discuss what is at stake for us personally and

> politically in composing autoethnography … and [3.] stage will pose the question of who and what we are performing in autoethnography. (Spry, 2011, p. 20)

To demonstrate the centrality of voice within text, personal narratives are written in layered accounts—merging story within story—elicited through the writing of the outer story. The outer story is one that chronicles my experience of stigma and discrimination within an organizational culture of policies, procedures, and administrivia. Methodologically the outer story has been written, double spaced, in 12-point italicized Times New Roman font (i.e., *Times New Roman font)*. Indented within the outer story, sub-stories—embodied experiences of narration, poetry, and prose—are written, double spaced, in 11-point Arial font (i.e., Arial font). Separation between outer and inner stories is demarcated with paragraph spaces surrounding a sequence of 9 tilde characters (i.e. ~~~~~~~~~) centered in the page. Notes, curriculum assignments, and transcripts inserted as part of substory text have been written, double spaced, in 11-point Courier New font (i.e., `Courier New font`). Images selected from the internet—artistic underwater photographs—have been inserted as figures to compliment written narrative. These photographic images provide a visual representation of my embodied experiences—from a place, space, and presence—where the use of language in the literary reverence of sensemaking falls short. Spry (2011) attributed this performative gap as the "skepticism of language's ability to represent embodiment" (p. 20).

The Subtext of Methodology

Autoethnography—as both process and product—seeks to describe personal experiences so that findings may be interpreted within the context of a larger social and political structure (Ellis et al., 2011, para. 24). Assumptions encompassed within this methodology hinge on my ability to recall and make sense of—to interpret—significant personal experiences. These may include: (a) recollections of incidents thought to have dramatically changed the course of one's personal life, (b) transformative experiences where crisis compelled one to critically evaluate the lived experience, and (c) situations after which life seems different, (Ellis et al., 2011, para. 32). Since interpretation and sensemaking of personal experiences are often subjective, there runs a risk that my interpretation and articulation of events may be perceived as partial, in favour of the narrator's position. Furthermore, where contradictions may exist between actual and perceived experiences, the translation of findings –within the larger social and political culture (of which the researcher has identified being part—may seem irrelevant and disconnected. To avoid what Habermas (as cited in Conle, 2000) referred to as the "dangers connected to the false presuppositions built into the grammar of fiction" (p. 57), Conle advised to keep in mind "the temporal quality of narrative inquiry … [and not to ignore] the dialectical relationship of the inquirer with his or her object of inquiry" (p. 58). Accordingly, as an autoethnographic researcher, I must ensure the analysis of my stories is based on sound methodological processes supported by current evidence-based research literature (Ellis et al., 2011, para. 33).

The Soliloquy of Truth

To recognize autoethnography as narrative fact centered on the understanding and response to the experience of story, it is important to acknowledge that the concept of fact—of "truth"—is relative in the framing and reframing of a person's stories. Accordingly, Bochner (as cited in Ellis et al., 2011, para. 32) asserted that queries of reliability are reflected in the narrator's credibility; likewise issues of validity are echoed in the story's authenticity. The narrator's storied accounts should seem plausible—like factual evidence that is able to conjure the emotions of experience it seeks to describe. Plummer (as cited in Ellis et al., 2011, para. 33) stated that the autoethnographic narratives should:

> Connect readers to writers and provides continuity in their lives. What matters is the way in which the story enables the reader to enter the subjective world of the teller—to see the world from her or his point of view, even if this world does not match reality. (para. 34)

In addition to credibility and authenticity, significant to autoethnographers is the generalizability of the research to the larger social and political realm. The attention of narrative transferability—from researcher to readers—is continually evaluated during the autoethnographic process. Readers draw comparison between their personal storied lives—and the storied lives of familiar others—to that of the storied voice of the researcher (Ellis et al., 2011, para. 35).

The Integrity of Story

Telling my story as my own is difficult, as much of my story is entwined within the storied lives of others: my family, friends and those that surround me. But this story—a performance in narrative—has been written from a very personal place—a privy space where *other* is cast in the role of supporting actor. And so, in writing about my experiences and relationships with Others, I am conscience to write from a place and a space that is ethically sound—a place and a space based on an ethics of care (Ellis, 2007). "As a genre of writing and research," Ellis (2007) further explained that,

> Autoethnography starts with personal experiences and studies "us" in relationships and situations. Doing autoethnography involves a back-and-forth movement between experiencing and examining a vulnerable self and observing and revealing the broader context of that experience. When we write about ourselves, we also write about others. In so doing, we run the risk that other characters may become increasingly recognizable to our readers. (pp. 13—14)

In a careful attempt "to protect the privacy and safety of others by altering identifying characteristics such as circumstance, topics discussed, or characteristics like race, gender, name, place, or appearance," (Ellis et al., 2011), I have used pseudonyms and taken literary liberty to adapt story details that otherwise may have contributed to character reveal. Yet in consideration of the relational concerns that emerge when writing about the intimate *other*—family and close personal friends, I

shared Ellis's (2007) sense of struggle—sense of duty—sense of care—when informing intimate others of how their storied lives have entered my story writing. When describing the intimate experiences of caregiving for her sick mother, Ellis (2007) wrote:

> My biggest fears in writing about my mother while she was alive included hurting her and the changing relational dynamics that might result … [As Ellis] described a scene in a hospital where I was taking care of my mother … because I described her body—the scars and bruises, loose skin and hanging breasts, bile and diarrhea—I felt reluctant to show this piece to my mom before I published it …. I feared my mother would become angry and tell me these aren't things you talk about in public …. However, not telling my mother about publishing this story felt ethically suspicious … [and so when Ellis] had another experience care taking my mom about which I wanted to write, because of the agony I had experienced not telling her about "Maternal Connections," [the first story Ellis wrote about her mother], I knew I could not publish anything that I didn't okay with her first. So I read the new story to her. (p. 18)

During the beginning of my writing process, like Ellis (2007), I contemplated keeping my writing secret from my family for fear that they might feel vulnerable and exposed—for fear that they might ask me to stop writing. Yet through the process of critical self-reflection, "by repeatedly questioning and reflecting on my ethical decisions, I have gained a greater understanding of the range of my choices

and the kind of researcher I want to be with my participants" (p. 5). And so, with my family, the stories I have written in this paper have been shared. Mutually we have come to an understanding—and agree to the sharing of our stories—in recognition that these stories and the writing of these stories have served as the instrument for which I have reclaimed my voice. It is through these stories I hope that others who identify with my lived experiences may be inspired to express their silenced voices too.

CHAPTER FOUR: THE PERFORMANCE OF STORY

> People tell stories not just to work out their own changing identities, but also to guide others who will follow them. They seek not to provide a map that can guide others—each must create his own—but rather to witness the experience of reconstructing one's own map …. Storytelling is for another just as much as it is for oneself. (Frank, 1995, p. 27)

Act 1: Background

To the "outsider" my stories may read as concise "factual" accounts of my experiences—a logical progression of events that encompassed a beginning, middle and end. The reality however—my "reality" however—is that my ability to live and relive my experiences in the process of sense-making was multivariate. Through the process of writing stories—new stories—new insights—new interpretations of my experiences—revolved and evolved in my head and on paper. Reliving these events tore open my heart and exposed the vulnerability of my humanness—the vulnerability of my soul. And so, through the process of performative narrative, the way I have come to think about myself in relation to my family, friends, and coworkers is chronicled as a learning transformation across the continuum of health, disability, and identity change. Stories as music—words as composition—through the stage and symphony of self-discovery, I better understand who I once was, who I am now, and who I am learning to become.

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The theme of stigma, disability and employment-related discrimination is far too familiar for persons who live the experience of "invisible" and/or episodic disability. Although legislation is in place to protect the employment rights of persons with these disabilities (Government of Ontario Human Rights Code, R.S.O, 1990), when entrenched in the experience of debility, enabling those rights in the face of bureaucracy is a practical impossibility (Fullick, 2008; Staurt, 2006). This is especially true when the nature of one's disability impairs cognitive functioning and self-advocacy skills … and so begins my story.

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My body cries an invisible identity.

I am a person, identified as per the Ontario Human Rights Code, with a medical disability.

Like many Canadians—I live the experience of a body that cries an invisible identity; an identity I have struggled to carry and conceal for the most part of my life.

From the "outside" my body appears "healthy", yet I was born with a degenerative vascular disease called hereditary hemorrhagic telangiectasia (HHT), a seemingly "invisible" condition in which the body—my body—creates fragile blood vessels that bleed through the skin, nose, and internal organs ("HHT Foundation International Inc."). Then, in my early 20s, after the birth of my first-born, I was diagnosed with bipolar disorder (BD), an episodic and life-threatening condition in which a person's emotions, energy, thinking, and activity levels—my emotions, energy, thinking, and activity levels—shift from
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manic to depressive extremes (Mood Disorders Association of Ontario, 2014). I inherited these health conditions through my parents.

From my mother, and she from her mother and grandmother before that, an arduous heritage was inborn in me—a bleeding disorder—a death blood of life—a guttered escape that transcends me to ground. From my father's family, a clandestine ignominy was passed down to me—a fire that graves the presence of passion—the family "hush-hush"—the cradle of my warrior salvation and tortured soul. Included from the internet, Figure 1, "Underwater view of a woman floating in water" by Tony Frissell (1947) is a photograph of a woman submersed just beneath the water's surface. The woman is wearing a soft white gown that flows alongside her body. I have chosen this photograph to illustrate my concealed identity—held in a suspension of lucidity—body separate from mind—hidden within its faceless image.

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Professionally, I have always done well. I am fortunate to find learning fun. I have always loved learning at school and learning at work. The more complex the assignment, the more I took pleasure "figuring" it out. Like a puzzle—always looking for the pieces to fit—I loved to take on challenges that were in disarray. School and work – puzzle solving served as a treasured solace—a place and a space where I could lose myself in the complexity and "sur-reality" of problems that were not my own.

And so, on November 25th, 2005, I took on the role of a research assistant—an apprentice puzzle solver as it were. I was hired by one of Canada's leading research
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Figure 1. "Underwater view of a woman floating in water" by Toni Frissell (1947). This photograph represents the embodiment of my concealed identity—body separate from mind—hidden within its faceless image.

universities as a full-time Research Coordinator. Within the faculty of health sciences, I reported to supervisor Dr. T and was responsible for supporting her research activities in two key areas. The first was within the university's research laboratories where I performed biochemical and body composition analysis. The second was within the hospital's in-patient wards and out-patient clinics where I coordinated several small to midsize clinical research studies, including the "HEALTH" study that was co-supervised by Dr. T and her colleague, Dr. P. Within the first year of my contract I received positive performance reviews from both Dr. T and Dr. P. Quickly I learned the intricacies of their research and was able to streamline processes that improved efficiencies and overall research quality. I was assigned the responsibility of training new students and staff who joined the project teams. At times there were up to 15 students working alongside me, and up to 300 children and families participating in the research projects I coordinated.

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Excerpts taken from Progress & Performance Review, March 28, 2006:

Dr. T: Excellent initiative in taking leadership role in diverse research programs; A delightful person to have on our research teams; Is already making a difference in productivity of research.

Dr. P: Taken initiative to improve working habits of staff/students. Eager to take on that role; Doing a great job
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taking over responsibility for running of HEALTH study – including good skills interacting with students & participants.

Excerpts taken from Progress & Performance Review, May 24, 2006:

Dr. T: Has re-organized lab to function in a much better way; Coordinates several studies easily; Outstanding accomplishments in 6 months.

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I loved the challenges and opportunities that work provided me. I loved learning about medical research and the complexities of health and the human body. I loved engaging patients and their families in the participation of clinical studies. I loved teaching and working with the students. I loved being surrounded by knowledge, questions, and answers. Finally I felt like I fit into a place I could call "home"—an escape from reality—a place where I was safe and confident in my ability to help solve puzzles.

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The "pit".

As a young child in kindergarten, on the "outside" I appeared healthy. I could run and play. I had friends, and I was a quick learner. I loved school and everything about learning.

For its time, my school was progressively built as an open-concept living and learning center. It was created in response to the Hall-Dennis report: "one of the most influential educational reports in the history of Ontario, written to

address the goals of elementary education" (Hall & Dennis, 1968). The school building itself was shaped like a honeycomb: six classrooms snuggled neatly into a hexagon, each framed by a single rear wall and two side-wall partitions. The classrooms surrounded a large open space in the middle, commonly referred to by teachers and students as the "pit"—a sunken gathering area, just a few steps down from the classrooms' upper level.

The pit was a place where students and teachers congregated each morning to sing the national anthem, recite the Lord's Prayer and listen to announcements before class. I remember sitting in the pit, tracing the outlines of its black and white checkered carpet floor with my fingers—getting lost in the pattern of its seeming perpetuity.

From the entrance of my kindergarten room I could look out across the pit and see the activities of other classes. Distinctly I recall standing at the "doorway" of my class peering into the grade 1 class beside me. Each day I would stand there and listen to what the older students were being taught. At home I had stacks of paper, crayons, and pencils. Often, in the wee hours of the morning, mind racing and unable to sleep, by the cover of my night-light, I stayed up late pretending to be in school—doing my "homework". Sometimes I would play the role of the teacher, and sometimes I would pretend to be a grade 1 student. I spent hours copying words from books and tracing their pictures onto scrap pieces of paper, carefully matching words with pictures. I loved doing school work; it kept me busy—helped me to feel confident in my ability—it was a pastime for which there wasn't room for me to be sad.

Distracted in thoughts of rainbow -coloured oil-water puddles at the side of the road as I walked to school one morning, I stumbled upon a dead baby bird lying on the sidewalk. The sight of the dead bird disturbed me; it absorbed me. It looked different from the pictures of birds I had seen in my books. Its body stuck to the concrete. Its wings looked like little baby arms—naked, with only a scarcity of fuzzy feather wisps that flickered in the breeze. Its head was slight and its face visible. Its eyes were open wide—blindly—staring at me. Its beak was open too—as though it were crying—silently—for help. Was he talking to me? Was he asking me to help him fly? Carefully I peeled his body from the wet pavement and flung him high above my head. He spiraled down in front of me. Why didn't he fly away? Trying again, I tossed him into the air a second time. Again he spun down to the ground and didn't move. Gently I slipped his dead body deep into my pocket and brought him to school in hopes that my teacher would know how to fix him.

When I showed my friends at school what I had found, someone told me that the bird died because it had been pushed out of its nest by its mother. I felt sad and confused. By the time my teacher noticed me holding the lifeless little creature in my hand, she shouted, "Susan put it down!" Immediately the bird dropped out of my hand and hit the carpeted floor. I started to cry. From the nearby classrooms, some of the older children, necks wrenching round, stood up at their desks to investigate the commotion. Shocked and surrounded by the watchful eyes of fellow bystanders, I froze—unable to hide. I wanted to crawl down into the pit where no one could find me. Included from the internet, Figure 2, by Viktor Lyagushkin (n.d.), "*Lady of the cave"* is a

photograph of a woman underwater—alone—swimming towards the entrance of a dark and forbidden cave. I have selected this image to symbolizes my echoing emotions transcending the pit—daunt in a sheltered escape— searching for something more.

For weeks, the image of the dead baby bird stuck in my head. At school I began to isolate myself from my friends, and I drew pictures of dead baby birds in my workbook. My teacher tried to talk to me about my "feelings" and the pictures I had drawn. I felt like I was in trouble. Notes were sent home to my parents, and meetings took place with a social worker. I felt ashamed. I wanted to hide—by crawling into the pit—so that my sad and confused feelings could be kept away from my teacher, my parents, and everyone around me.

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The next 3 years skipped by like a heartbeat. My working relationships with Dr. T and Dr. P remained quite positive as I continued to excel at my job. My workload was demanding, and my schedule was hectic. I "juggled" priorities in order to make the most of scare resources. I developed networks of friends—colleagues—who provided me and "my" students with guidance and access to equipment and resources that helped our work. I became skilled at navigating the convoluted systems of administration within the university and hospital—two distinct and separate workplace organizations, interconnected in the establishment of a larger governance organization—an academic teaching and research hospital. The environment was intellectually inspiring; I loved it. Work exposed me to new ways of thinking—about subjects and ideas that I never would have imagined on my own. At
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Figure 2. "Lady of the cave" by Viktor Lyagushkin (n.d). This photograph symbolizes my echoing emotions transcending the pit—searching for something more.

home I stayed up late reading journal articles, learning about new concepts from work that sparked my curiosity.

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I am a nighthawk.

I am a nighthawk.

Not an owl—but a hawk. I am a bird that soars through the sky – alone making no nest my home.

I work in the wee hours of the night—by the flicker of a candle or by the glow of the TV light.

The sound of the keys clicking and tapping. I type faster and faster and faster. The space bar plunking down harder and harder. When I feel that the words are right—right to write—then I am free and can type super F-A-S-T.

I love the night hawk—that doesn't travel in a
flock. It surveys the world from above—from afar.

Its terrifying squawk.

Its call so distinct—so succinct to the mood of the night and to the beat of my heart.

I watch in splendor as it circles above. The hair on the back of my neck stands straight.

I feel the intensity of its focus—thriving—diving—its swoops to the ground for its prey, but only for a flash.

Like the glare from the morning sun across the stony water ripples—cold. And so, the night hawk soars bold—never dying away—never controlled.

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As challenging as some of my tasks were, I found them to be fun and exciting. The best part of my job—"hands-down"—was working with, teaching, and learning from the students. I loved this aspect of my job so much that I invested a considerable amount of time and energy in the development of learner-centered teaching practices. In order to teach more effectively and inspire the students to reach their fullest learning potential, I enrolled in a Bachelor of Adult Education degree program through Brock University. Looking back, I now realize how important that decision was—and how it transformed my outlook on life and my career goals.

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Memoirs from a happy time.

After "closing the book" on the painful memories that involved my departure from the university, it is only now that I am able to go through my files and notes to make sense of those experiences. Reading and rereading the countless "thank you" notes I received from the students I taught, learned from, and worked with over those years makes me feel both incredibly happy and sad at the same time. From them I learned so much—more than they probably realized—more than I ever taught them. I am happy to have had the opportunity to be a part of their life and education—sad to have had to—STOP—let go—and move on. Included from the internet, Figure 3, by Isle Moore (n.d.), "Wonderland couture" is a photograph of a woman underwater—eyes open, body upright—with a notebook and its pages swirling around her. As
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paper memories swirl around me, this photo embodies my conflicted thoughts and emotions—wanting, yet not wanting to “move on”.

Taken from some of the “thank you” notes I received from students, the following passages represent the learning relationships “my” students and I shared.

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Dear Susan,

Thank you for such an amazing experience. Starting from June last year to now, I have learned so much. I came in with not a lot of experience and I feel like I’m leaving with a head full of knowledge. Thank you for all that you’ve done for me and the other students. Thank you for constantly nurturing and encouraging us as we continued our undergraduate thesis work.

Sincerely, AB

Dear Susan,

Thank you for your guidance, support and unwavering faith in my abilities. It was truly a pleasure to work by your side. Your dedication to your work, your excellent people skills, and the easy grace and diplomacy you apply in dealing with obstacles was inspiring. You taught me a great deal in such a short time and I’m saddened that it was over so soon. I now realize how much work you put
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Figure 3. "Wonderland Couture" by Isle Moore (n.d.). With paper memories swirling around me, this photograph embodies my conflicted thoughts and emotions.

into securing my placement with your team and I thank you. Thanks, JD

Dear Susan,

I can’t believe it’s time for me to leave already. I don’t know how to thank you for all your help, encouragement and kindness for the past 3 years! Thank you for always believing in me and teaching me some important things regarding the workplace and life in general. You are such a great role-model for women! Your attention to detail has

taught me a lot. Thanks for the wonderful opportunities to improve my skills. Thanks for all the advice and guidance. Thanks for being positive and listening when I needed that the most. I will never forget your kindness! Love, TG

Susan,
Another summer came and went so fast,
Working in the lab has been a blast!
Susan we just want to let you know,
You’ve taught us so much and helped us grow.
We love your laugh and positive spirit,
For all your help, you deserve much merit.

You always take time to guide us along,

And keep us organized so nothing goes wrong!

Now it's time for us to go our separate ways,

But before we leave, we just wanted to say:

Thank you Susan for all you have done,

We learned so much and had tons of fun!

From the Summer Lab Ladies, AS, KR, FF, KM, MK, LR, TG

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Act 2: Rising Action

> A narrow medicalized view of suffering, as solely defined as physical discomfort, ignores or minimizes the broader significance of the suffering experienced by debilitated chronically ill adults. The nature of that suffering is, I contend, the *loss of self,* felt by many persons with chronic illnesses. (Charmaz, 1983, p. 168)

By the fall of 2008, I had developed several instructional resources in the areas of laboratory safety, research ethics, and research project coordination for the training of new students, staff, and volunteers. Through my Bachelor of Education studies, I actively continued to learn and refine my adult education teaching practices. At the same time I completed a postgraduate diploma in clinical research in order to improve my technical knowledge and teaching.

Working while going to school was an ideal situation for me. Coursework provided me the opportunity to critically reflect and evaluate the effectiveness of my work-related teaching and learning practices. It also inspired me to examine the role
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that I played in my organization—as a learner, teacher, and employee with invisible and episodic disabilities. Likewise, working within the structure of an educational organization, I was able to explore the role of educational theory in practice and how that knowledge impacted me as a learner, teacher, and employee with disabilities. Included from the internet, Figure 4, by Carlos Contreras (2010) "10 metros de chiffon" is a photograph of a woman underwater—sitting upright, arms curled round legs, hands clutching toes, face down, eyes closed. Motionless and enveloped in a sea of white fabric the woman sits waiting. This photo signifies the unfolding of my changing role and identity as a teacher, learner, and advocate—disrobed by the cloak of visibility.

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In response to excerpts taken from my early course assignments, questions related to the emergence of my teaching and learning identity—as a woman with invisible and episodic disabilities—began to surface. Through an evolving and interactive process of foresight and retrospection, a voice of advocacy started to resonate from within me.

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The voice of an emerging advocate.

The following passages, excerpts taken from course work and assignments, provide a glimpse into the emergence of my voice and my identity as an educational advocate. Revealed in these passages are critical reflections about my own learning experiences. Critical reflections that

Figure 4. "10 metros de chiffon" by Carlos Contreras (2010). This photograph represents the unfolding of my changing identity—disrobed by the cloak of visibility.

question the inclusiveness of the organizational learning policies and practices that were prevalent in my work environment.

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May 16, 2008 – Assignment #1: Perspectives on Adult Education.

I believe that knowledge is created from unique personal experiences—subject to individual interpretation within the context for which learning takes place ….

Cultivating an atmosphere of fairness and equality involves facilitating the interchange between traditional knowledge concepts with new ones. Content and context moves to the background and the learners become forefront and center in the creation of new knowledge concepts.

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What triggered my awareness that educational equality depends on the integration of new knowledge concepts into the hierarchy of traditional learning theory? Why did I view learner-centered practices as critical to educational equality? What were my feelings about educational fairness and equality? What factors in the atmosphere of my work environment contributed to these feelings?

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June 5, 2008 – Assignment #2: Teaching Practicum.

Until reading a paper about learners with learning disabilities (Beverly Sandock, 2003), it never really occurred to me that some individuals with learning
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disabilities might not disclose the nature of their disability, "hidden disabilities" to their educators, especially at a college or university level.

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Why was I surprised to that learn that some individuals with disabilities may try to conceal their disabilities in the context of adult education environment? Is this the point at which I began to acknowledge myself, as a teacher and learner with "hidden disabilities"?

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June 16, 2008 – Assignment #3: The Reality of the Situation.

Situated learning moves our focus from schemas, inside the heads of individuals to the social contexts of participation and learning which are rich and complex with meaning. Within situated learning there is reciprocity between individuals and social groups. Thus, a central idea embedded in situated learning is that the product of learning cannot be reduced to cognitive structures (i.e. schemas), but must acknowledge the larger changes in the social order and work of a community (Pratt, 2002, p. 87) …. To foster a supportive learning environment for adult learners with disabilities, they must be encouraged to draw from their individual experiences and personalize learning

objectives and training activities. This sets the stage for adult learners with disabilities to achieve their full learning potential.

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Why were my views of traditional knowledge concepts changing to recognize the value of participatory learning? Having always felt safe, secure, and excited in a learning environment, would these feelings change if I were to disclose the nature of my disabilities to my supervisors at work? As a teacher and learner with disabilities, in what new role did I see myself?

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My evolving identity.

I never realized—until I got sick—that being a teacher meant being an advocate—searching to discover myself—questioning who I once was, who I am now, and who I am learning to become.

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In the fall of 2008, I experienced a series of trans-ischemic attacks (TIAs), frequently referred to as "ministrokes". Magnetic resonance images (MRI's) and computerized tomography (CT) scans showed evidence of recurrent lacunar infarctions in the left parietal lobe of my brain.

Similar to strokes, TIAs have the same symptoms—paralysis on the side of the body opposite to the affected side of the brain, sudden weakness or numbness, slurred speech, blurred vision, and mental confusion. TIAs also share the same underlying cause as strokes—an interruption of blood flow to part of the brain. Unlike strokes
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however, the interruption of blood flow to the brain as a result of a TIA may resolve within minutes or hours (Pubmed Health).

In retrospect, I now realize that this series of strokes may have affected me more dramatically than I cared to consider at the time. Perhaps I was in a state of shock. Perhaps it was easier to submerse myself into denial than accept the fact that my body was changing—that I was changing. Perhaps I wanted to dissociate myself from the fear of living in a body that was broken.

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Trapped inside my body.

That morning, upon waking, my body trapped me inside.

From its solid icy grip—skin--flesh—and bones—my body failed to unleash me to movement. Relentlessly—restlessly—a fog of disorientation struck me helpless.

Unable to move—unable to make sense of my body in relation to my bed, the floor, and the walls of the room that encased me, I wrestled—without motion—in the cemented weight of my body. I was stuck in some sort of space—halfway under—not sure how to surface. Staring down at my body— outside of myself somehow—I paused. Included from the internet, Figure 5, by Elena Kalis (n.d.) is a photograph of a woman under water—legs positioned up towards the surface—arms suspended straight from the side. This photograph illustrates the disorientation I felt—upside down in water and unsure which way to swim— trapped inside my body.
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Figure 5. “Underwater_dark01.jpg” by Elena Kalis. This photograph embodies how I felt in suspended in disorientation—trapped inside my body—upside-down in the water and unsure which way to swim

An intensity of pain shot deep through the left side of my head. Like the impale of a lance—gravely burrowing into my brain—its position held strong. Then, somehow … somewhere … in the seconds of an eternity … it faded away … into a dormant haze.

Only after the pain had passed did I become aware that my breath and beating heart had stopped.

Feeling so completely exhausted—my head stuck to my bed—hair glued to its pillow encrusted in dark crimson blood. My nose bled through the night. I was tired—so very tired. I wanted to get up out of my bed, but I couldn't. I tried to move my right arm but it was so heavy. I tried to call but words were stuck in my head—stuck in my lips. I tried to lift myself out of bed but instead I fell to the floor. My son must have heard me fall and called an ambulance. I remember being in the ambulance—on a stretcher. My feet felt cold.

From the hospital bed, in the distance, I heard a toilet flush. Its sound—the note of a body working—contrasted my own body stopped.

Within a week, my senses recovered and I was back at work—back into the safety of what felt like "the pit"—a place where I could work and forget about myself—my reality.

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In January 2010, I returned to work after a 12-week medical leave related to depression. I was coming to terms with the fact that my body had changed—that I had changed. Tasks once so simple now took their toll. Sometimes just walking up
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stairs wore me out. I took the elevator a lot. My physical inactivity caused me to gain weight. It was tough maintaining the busy pace I once relished.

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Gripping the wheel.

My heart races along with the sound of passing cars. My lungs fill with air—deeply—then I exhale a sigh that echoes through me—didn't realize I was holding my breath until I exhaled—and felt my world stop.

Loosening the grip of my hands on the steering wheel, tiny red blotches—some that have bleed open—contrast the stark whiteness of my hands and fingers.

My skin—so thin—blue velvet veins—veiled in translucency—a persistent reminder of my illness—visibly hiding in the skin that I am.

My body is solitary.

I don't recognize myself.

I draw back out of auto-pilot, carefully surveying the surrounding traffic from my side and rearview mirrors.

Along the gravel shoulder I have stopped—to breathe.

All I can see—all I can feel—are vehicles rushing past me.

Life is racing past me—through me—in the blink of someone else's watchful eye.

From myself I am severed—disconnected—without feeling.

I drive home to cook dinner in the light of a sunset echo.

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The HEALTH study that was cosupervised by Dr. T and Dr. P had achieved its participation capacity, so there was a ton of work that needed to be done. Multiple study visits needed to be coordinated and pages of data needed to be reviewed. During my medical leave, Dr. P hired a part-time assistant, SP, to help. Upon my return to work, I was tasked with the role of training SP—bringing her up to speed on the processes and procedures involved with the HEALTH study—training her to be my "back-up" so to speak.

Meanwhile, at home, my mother's health had severely deteriorated, and my son, like his mother, was struggling with bleeding and depression. In my mother's body—through her stomach and intestines, blood drained like a sieve. Anemia made her weak, confused, and emotional. It was difficult to communicate with her at times. Her medical team conspired to remedy her with a series of blood transfusions—blood from someone else's body pumped into her veins. This made me feel angry and upset—angry at the doctors and the medical system that governed my mother's health—upset at the temporality of her care—upset at the treatment that was offered—a bandaid solution at best. In my head I felt conflicted—I questioned my mother's reasoning for holding onto a life that was quietly bleeding her to death. I started to think—what did this mean for my son and me? Would we be forced to live out the same legacy as my mother? What if we didn't want to accept "treatment"? What if we didn't see ourselves as broken or needing to be fixed? Would we fall victim –steam rolled by the ravenous machine of health "care"?

In my body and mind, I tried to stay afloat—tried to stop myself from sinking into the darkness of despair—of disparity—but it was difficult. It was difficult for me to get up in the morning—difficult for me to get ready and go to work. I waited, sometimes hours, until my nose stopped bleeding long enough so I could get dressed. Then, in the next room beside me, my son experienced similar issues. He was so pale—ghost white. It was so difficult to get him out of bed and so he could go to school. Within that year he missed over 80 days of classes. On days that my husband wasn't able to work from home I relied on my father to sit with my son while I dragged myself to work or dragged my mother to the hospital. It was an exhausting interplay of caregiving—caretaking—and caregiving some more. Seeing my son so sick, my mind regressed to a time when I was very ill, confused, and depressed—the earliest memories of my life with my son—before and after he was a baby.

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Survival.

The year was 1994. My husband and I had just married in June. The two of us worked together at a small contract pharmaceutical manufacturing facility. We were "lab rats". Our job was to test chemicals—hundreds and hundreds of chemicals—both individual raw materials and finished pharmaceutical preparations - to ensure they passed quality and safety standards. More than half of the work we performed had to be done in a ventilated fume-hood because the chemicals we worked with were either toxic, carcinogenic, flammable—or all three. While in the lab we wore
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protective clothing: lab coats, gloves, safety glasses, and activated charcoal gas masks (when needed).

Sooner than we had expected, by the fall of that same year, I became pregnant. Physically my body was healthy enough to sustain a pregnancy— and the preliminary ultrasounds and blood tests that my doctor performed showed that “it”—my baby—was strong and healthy too. My mind, however, was unsettled. Within weeks of discovering that I was pregnant, my mood started to change drastically. I was scared that “something” was wrong with “it”. My heart ached all the time, and always I felt scared. I had a sinking feeling that somehow, unknowingly, I exposed myself to toxic chemicals while at work. I was frightened that “it” would be born hurt and disadvantaged.

Three months into my pregnancy I could no longer work. I was terrified of chemicals and of the lab. I cried all the time, and I had no energy to do anything. All I wanted to do was die and escape the possibility that something was wrong—that I had done something wrong—that somehow I had hurt my baby. Mentally, I found myself stumbling—plummeting down a dark spiral of despair—unable to secure my footings—unable to keep myself from falling.

When I slept—my head was full of nightmares—images of extreme horror. I imagined that my baby was being murdered—his body being dismembered—tortured—killed with chemicals so that he couldn’t see, talk, breath, or move. I was scared that he would be disfigured. I was scared that he would be born developmentally delayed—vulnerable—and that society would be cruel to him because of his vulnerability. I was powerless— paralyzed and trapped inside my body—to stop whatever evil I imagined was

hurting my baby. I wanted to punish myself for not being able to “save” him— for not being able to keep him safe—from becoming vulnerable.

Quickly my depression caused me to gain excessive weight. I had letgo of my appearance. I slept and ate all day and all night. I didn’t shower or change my clothes for days on end. By month five I could barely talk. I was completely despondent and suicidal. My husband was worried. My family doctor referred me to a psychiatrist, where I was diagnosed with bipolar affective disorder. I didn’t want anything to be wrong with me—or my baby—and I didn’t want to risk the possibility of side effects by taking medication. I wanted to hide—to fall asleep and never wake up. Against my psychiatrist’s advice, I refused pharmaceutical treatment. I continued to spiral down into darkness. I slept in my bed for the last few months of my pregnancy—surfacing only to eat, use the bathroom, and attend doctors’ appointments. I had cut myself off from my friends and family—all except my husband. He stayed by my side and took care of me.

Then—in the wee hours of a summer morning, my son was born. He was perfect. Strong and healthy, he looked like an angel. I felt undeserving to have him. I didn’t know why God had entrusted this precious little miracle to my care. I was confused and unsure of myself. I thought I might be living someone else’s reality—and pretending to be in love with someone else’s perfect little boy. Included from the internet, Figure 6, “Mother and Baby*”* by Zena Holloway (n.d.) is a photograph of a mother underwater, holding her baby in her arms. This photograph embodies my feelings after giving birth to my son—holding him safely in my arms and kissing him gently.

Figure 6. "Mother and Baby*"* by Zena Holloway (n.d.). This photograph my feelings after giving birth to my son—holding him safely in my arms—kissing him gently.

In the hospital delivery room, while holding my son and looking deeply into his gorgeous blue eyes, I knew that I needed to be stronger. I knew that I needed to get healthier—for my son, my husband, and myself. In the weeks and months following the birth, determined, I adhered to my psychiatrist's medical advice. I began to recognize the severity of my mental illness and how it had affected me as a child, teenager, and into adult life. Actively I made a commitment to myself and to God to work with my psychiatrist in order to get "better"—to be able to better care for myself so I could care for my family. It took several months before I was well enough to smile, laugh, and feel confident again, but I had changed. No longer was I the person I once was—I became a "patient"—a person with mental illness.

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Bleeding from the outside in.

As a child and teenager, I recall several incidents where I saw both my mother and grandmother bleeding—a lot. From the nose, mouth, gut, and even skin—always so much blood. The spontaneity and intensity of these episodes terrified me. Like a haunting privacy, the following passages are foreshadows into my adult life. Included from the internet, Figure 7, "Underwater dance. Red tail" by Vitaliy Sokol (n.d.) is a photograph of a woman gliding underwater with her face-down, body concealed in red fabric. This photograph embodies my legacy—life in a veiled blood pool.

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Figure 7. "Underwater dance. Red tail." by Vitaliy Sokol (n.d.). This photograph is my embodied legacy—gliding through the water in a veiled blood pool.

Blood line #1.

Finding my mother, lying on the floor … unconscious.

Blood spilling … out of her head.

The dog laps its crimson seepage.

Seeing the blood – her blood - leak across her lifeless body,

Panic cuts deep into my veins.

My insides turn cold - my skin retracts from its outer layer.

Paralyzed, I plummet to action.

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Blood line #2.

In the cloak of night, witnessing my grandmother, Hands

and knees on the icy tiles of the bathroom floor,

Towels and a bucket in toe, mopping up a pool of redness.

Ringing the blood-stained cloth into the bucket

Desperately, trying to clean up the mess - without waking anyone - before anyone saw.

I hid in fright …unsettled … in the shadows behind the bathroom door,

Looking into a scene that someday would play out to be my own bloody déjà vu.

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Act 3: Turning Point

In the traditional view of workplace diversity, visibility of the difference has been a prerequisite to experiencing the negative effects of diversity on social integration, communication, and group conflict. These categories of difference

> are laden with meanings triggered by their visibility, meanings which are created and reinforced in social interaction. The dynamics of invisible differences are more complex. Social interactions involving differences such as religious beliefs, illness and disability status, or sexual orientation are also socially meaningful differences, but they may not be recognized in every interaction. Visibility, therefore, is a central factor in the management of and reaction to a stigmatized social identity (Crocker et al., *1998*; Jones et al., *1984*) … Invisibility creates a dilemma for employees seeking the benefits of legal protection against discrimination in the workplace because to receive the benefits they must first disclose their situation. Yet the act of disclosing their difference is potentially career limiting because in doing so they create the grounds for possible stigma and discrimination. (Beatty & Kirby, 2006)

Within a few months of returning to work, my work environment turned hostile. By the spring of 2010 SP had let loose her frustrations on me. Compared to so many of the students I had trained, everything I did with SP seemed complicated and laborious. Tasks once so simple grew into colossal training hurdles that dragged on for weeks. During times when I was assigned to work on other projects, SP would interrupt me—everywhere—with a barrage of HEALTH study questions—in the labs, in the clinics, in the offices, in the cafeterias, even in the bathrooms—she just wouldn't stop. What a nightmare! Continuously I revised the study's written operational procedures in order to include the level of instructional detail that "made sense" to SP, but it never seemed to be enough. SP was resentful and

verbally aggressive towards me. She was critical of the training instruction I provided and described it as schizophrenic. She made derogatory comments about my weight, my "meds", my mood, and my mental health status. Several times I asked SP to stop making such comments—but she persisted. I was surprised by her tactics—and her relentless ambition to wear me down. I felt overwhelmed—challenged to balance my workload priorities and train SP at the same time. I knew that SP was struggling to understand her job—and I knew she was struggling at home with her family as well. I just didn't have the stamina to deal with SP or her issues. I was challenged enough to deal with my own. My psychiatrist supported my return-to-work plan by writing a statement to the university return-to-work specialist, WW. This statement identified me as a person with mental illness, and it outlined my need for modified workplace accommodations.

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> Attending Physician Statement – April 28, 2010:
> Scheduled Modifications: Flexible start time; Option to work from home, as needed; Uninterrupted work time – communication by appointment to prevent interruption of work and concentration.

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I attempted to keep Dr. T and Dr. P in the loop—but it was difficult. I struggled not only in my recovery from depression, but also with trying to conceal it. When I spoke, sometimes my voice couldn't find the right words—they got caught on my tongue or drifted silently through the air. I stammered and stuttered. I was

embarrassed and tried hard to conceal my other life—my life with mental illness—my life of blood-soaked pillowcases—from the people I worked with. My exhaustive effort to keep up the façade, however, only hurled me deeper into the depths of despair—a disability paradigm—where I was faced with the dilemma—the dread—of deciding whether I should or shouldn't disclose the nature of my disabilities—my mental illness in particular—to those that I worked with—in order to receive help. This fear—this anxiety—became all encompassing. It was easier for me to talk about the physical changes that were happening in my body—nose bleeding, internal bleeding, headaches, cold hands, cold feet, broken capillaries, and so on—rather than to discuss how my mental illness was affecting me. I found myself lost in thought, not sure how to manage—how to communicate—information about my job to my supervisors.

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Lost in thought.

Most of my "important" work—my creative work—is conceptualized. I see the solutions in words and through images. I feel the answers in my skin—pulsing through my veins. Feeding my soul—my being—my essence—I am lost—in thought.

My thoughts are a collection and reorganization of everything I have experienced with others—through others.

My thoughts are my life—a life that is sometimes unable to communicate with others—because words do not convey in adequacy their meaning.
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For almost five years I kept hidden the secret of my mental health condition from those that I worked with at the university. Fearful of stigma—of being labeled and placed into the category of "other"—I chose only to disclose the nature of my mental health disability at times when I felt "safe"—secure in my body—in my mind. I chose to disclose the nature of my mental health disability only to those that I felt I could trust to be open-minded and unprejudiced by fear or stereotype. My supervisor, Dr. T was one of those people. Dr. P, on the other hand, was not. Dr. T was more understanding—more experienced and capable of managing diverse work teams of people with different work styles and abilities—teams of people who were different.

After months of enduring snide remarks from SP, remarks that were unprofessional and discriminatory, reluctantly I decided to take action. I wanted to avoid further confrontation with SP, so instead of "ratting" on her, I tried to handle things more "professionally" and less "tattle-tale" like. To Dr. P and my manager, CD, I attempted to describe how my work environment was contributing to a serious relapse in my health. Nervous—that once the skin of my unseen identity was ripped open—I would be pitied—regarded as weak—as broken—perhaps even incompetent or incapable of working. To Dr. P and CD, I did not identify myself as a person whose emotions had turned fragile as a result of a relapse; I did not identify myself as a person with bipolar disorder. Warily I wrote.

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E-mail Sent: April 21, 2010, 06:58:30

Last week in particular was very difficult on me. Finally, after giving much consideration, I made an emotional and very difficult decision, supported by my doctors, to speak to the university's occupational nurse and identify myself as a person with a medical disability. There are elements of my work environment and job function that have been increasingly difficult for me to perform and the consequences of me continuing to do so, may put my life at risk. I met with the university's occupational nurse to discuss my situation in detail. A few months ago I needed to take time off work while I dealt with some medical concerns …. The process by which I returned to work and the environment I was placed in was not and is still not conducive to my ongoing wellness.

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After writing the e-mail—that e-mail—requesting help—things only seemed to get worse for me at work. Meetings were scheduled. Dr. P and CD wanted to talk with me. At first, I thought they were trying to help me—trying to understand how work was contributing to a relapse in my health. Little did I know however, SP had fabricated tales about my work performance and—with a smile and a chuckle—had influenced Dr. P and CD to view me in a negative light.
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Unlike my supervisor Dr. T, when Dr. P and CD spoke to me—I felt like I was being interrogated. I felt I had to defend myself for needing disability workplace accommodations. I felt like I had to "prove" to them that I was sick. I didn't understand why Dr. P and CD wouldn't accept my need for disability accommodations as something that was "real". I didn't know what to do—I didn't know who I needed to talk to in order to make things "right". I tried to share with Dr. P and CD some of the details about SP's behavior towards me—in hopes that it might spark them to take action and remedy the situation—but unfortunately nothing changed—and I unraveled even further.

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E-mail Sent: May 5, 2010, 14:39:22

It is with much regret that I am writing to inform you about some of the difficulties I have been experiencing with one of my colleagues, SP. Over the past several months she has made hurtful and derogative comments about my mental health status. These comments have made me feel very embarrassed; it has added unnecessarily to my stress… SP has accused me of providing her with schizophrenic training …. SP made another comment, 'it's the meds. that are causing you to gain weight' …. I asked SP not to make comments about my moods or mental health issues anymore.

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I ended up getting so sick—falling to the point that at work when SP was around, I cried. I couldn't even bring myself to look at SP or listen to Dr. P or CD talk about him. My emotions had taken the best of me—leaving me fragile, vulnerable and broken.

Looking back, I feel sad and embarrassed—realizing how sick I really was. I regret having exposed my fractured self and fractured mind to Dr. T, Dr. P, and CD. It must have been confusing and difficult for them to see me as I was—a shell of a person with the blood, bones and guts of my emotions flailed on display. Included from the internet, Figure 8, by Elena Kalis (n.d.), is a photograph of a woman underwater –hair swirling around her – holding a turtle shell in front of her chest; fused to the underside of the turtle's shell, exposed are its backbones. This photograph embodies my empty emotions—revealing my broken inner self - my bones.

Like black and white—diametrically my disposition had changed over the course of a few months—over the course of a few weeks—over the course of a few days. I went from high-functioning, capable, professional—able to take care of myself and my family—able to excel at my job—able to excel in university course work and professional development opportunities—to a plummet of despair and interruption.

Emotional, despondent, sluggish, tired, unable to take care of myself and my family – struggling to manage day-to-day activities and responsibilities within my job

Figure 8. "Underwater_elena_kalis21.jpg" by Elena Kalis. Exposing the blood, bones, and guts of my emotions—this photograph embodies the shell of a person I once was.

and within my life. Later I discovered that Dr. P had made inquiries amongst the student about my changed mood.

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Hand-written note by Dr. P - appears to have been dated May 5, 2010, 1 p.m.

Met with Susan in corridor. Responded "it was a bad day" when asked how she was. When asked if I could help in anyway replied, "I don't think I can work for you anymore. I cannot go through my days like this". Had just met with CD. Apparently confrontations with SP. Concerned SP made derogatory comments re: her moods. I have asked her to document in writing. Proceeded to ramble …. Concerns raised by [students] LP and AH about recent interactions with Susan. AH and LP noted when asked how she [Susan] was, replied "Sad. Very, very sad."

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Just seeing those words in writing—typing them—brings back memories of being stuck in a very dark place. I am moved to tears, and my heart aches. I feel sad that I wasn't able to hide my depressed feelings from the students. Desperately I wanted my workplace situation to improve—and the only way I saw out was for me to remove myself from the harassing situation—at least until I was strong enough—well enough—to deal with it through the "proper" human resource channels. I felt

trapped—constricted—not sure what to do—not sure how to cope. Included from the internet, Figure 9, "Into the Abyss-1" by Simon Harsent (n.d.), is a photograph of a woman underwater—ropes tangled around her arms. Sinking deep to the bottom of despair and unable to free myself, this photograph is my embodied self—alone drowning in the shadows of darkness.

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By the middle of May 2010, supported by my psychiatrist, I ended up taking another medical leave related to depression—it was the only way I could alleviate the stress and the tension I was feeling at work. A few weeks later, with adjustments to my medication, I felt well enough to return to work. I wanted to return to work--work was important to my recovery. Work was a necessity for me; it helped remind me of my self-worth and created a sense of belonging for me. My psychiatrist shared this view and supported my return to work by writing a letter to the university's return-to-work specialist.

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Attending Physician Statement – June 1, 2010:

In order to facilitate a successful return to work I recommend that Susan's work load be reduced but not her hours … and that her responsibilities be confined to those that she manages with one physician – specifically Dr. T.

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Figure 9. "Into the Abyss-1" by Simon Harsent (n.d.). Sinking deep to the bottom of despair—unable to free myself—this photograph is my embodied self—alone drowning in the shadows of darkness.

During the weeks that followed, I was beginning to see light through the murkiness of my depression. I worked full-time in Dr. T's lab and research offices—away from SP for the time being. I looked forward to getting back into the swing of things without the added stress and tension of having to deal with the harassment from SP.

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My mentor my tormentor.

Dr. T was an experienced researcher and savvy tenured professor. She was clever and articulate; a person who made the grueling task of manuscript writing appear effortless; a person who had mastered the art of teaching; a person whose reputable status permitted induction into the academic realm of intellectual politics and organizational power. Dr. T was once my professor—and also my supervisor.

Working for Dr. T was like living on a Hollywood set. Upon entry to meetings she announced her presence with sparkle and style—donning designer suits—hair and makeup immaculate. Outwardly amongst her peers, Dr. T poised herself and her research agenda forefront and center; some may have considered her research passion as egocentric. Yet within the privy of her inner circle—of which I was once—pinned to her swanky suit sleeves, Dr. T wore her heart. In the quiet of her office—in her den—I served witness to her deep-rooted emotions—the rawness of her pain, love and concern for her husband, her family and friends. Like all—she was vulnerable to personal attacks by rival colleagues and discontented students. She was vulnerable to stains that threatened her
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being—her existence—her protected world of ivory towers that had become her fence—and her prison—part of a severed identity.

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Then came the incident—the climax to this story as it were.

On June 21, 2010 I was called to an unexpected meeting with CD and the return-to-work specialist, WW. During this meeting, I was presented with a document designed to "facilitate" my return to work. The document indicated I would be "accommodated" for 6-months with full-time pay, having to work only part-time hours, and, on the basis of my health condition, I had to resign my work on the HEALTH study.

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Return to work document, prepared June 10, 2010 by Return to Work Specialist WW.

Without Prejudice & Precedent

To enable the department to maintain the level of service required … we would like your acknowledgement that you agree it would not be in your best interest, due to your health concerns, not to return to your previous role.

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At first, I thought a legitimate error had been made. Inside my head I was sure that an institution such as a university—a place of "higher" education, dedicated to the discover of knowledge and its dissemination—would be knowledgeable and capable of accommodating the disability rights of its employees. I cited my concerns.
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I questioned why the university would pay me full-time wages for 6-months while requiring me to work only part-time hours. WW jested and told me that I was lucky to be paid full-time wages for working only part-time hours and that I should view the situation as a vacation—as a "bonus" so to speak.

On my chair in the meeting room I sat quietly—in shock—trying to rationalize what WW was telling me. It didn't make sense. Confused and unsettled—a growing feeling of dread began to entrench me. My body felt cold and numb. My head started to spin, and I felt sick to my stomach. Inside my head I questioned the reality around me—was this really happening to me? Was I being "fired"—strategically redeployed—because I had come forward as a person with mental illness? Included from the internet, Figure 10, "Underwater art 1" by Brian Stevenson, is a photograph of a woman underwater. The woman's arms and legs are flayed around her—body and head constricted. With my head spinning and unable to make sense of my experience, this photograph embodies my confusion.

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Act 4: Falling Action

Work is a major determinant of mental health and a socially integrating force that is highly valued. No single social activity conveys more of a sense of self-worth and social identity than work. To be excluded from the workforce not only creates material deprivation but also erodes self-confidence, creates a sense of isolation and marginalization and is a key risk factor for mental disability. For people with a serious mental disorder, employment is an
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Figure 10. "Underwater art 1" by Brian Stevenson (n.d.). With my head spinning and unable to make sense of my experience, this photograph embodies my confusion.

> important stepping-stone to recovery. It is a normalizing factor that provides daily structure and routine, meaningful goals, improves self-esteem and self-image, increases finances, alleviates poverty, provides opportunities to make friendships and obtain social support, enriches quality of life and decreases disability. (Staurt, 2006, p 522)

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Struggling to make sense of my experiences, I needed to know more. I needed to understand. Within days after my return- to-work meeting, I contacted the university's human rights and equity services office to discuss the events surrounding my experiences of discrimination. The officers I met with found my case to be unsettling, and for the following 9-months, they attempted to remedy my situation, trying to derive some sort of a resolve so that I might regain my lost dignity and make myself feel whole. It was a difficult process—trying to fill in the gaps.

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Filling in the gaps.

Filling in the gaps is painful; they are entrenched in the rawness of life's flawed edges.

Gaps make my head hurt.

Gaps make my heart ache.

Gaps hold insight into past experiences that have left me hurt, puzzled and confused.

Gaps make me feel broken, helpless, and ashamed.

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The effects that my experiences of discrimination—of losing my job after identifying myself as a person with disabilities and identifying my need for workplace disability accommodation—was devastating—for myself and for my family.

With the loss of my job, I felt the loss of my dignity. I felt the loss of my identity, and the loss of my sense of belonging. Because my mental health disability had been identified at work and it served as the basis for which I was relegated to part-time employ—strategically cast aside, I felt like "less of a person". I felt sanctioned, isolated, and marginalized. My self-confidence shattered and my self-worth were affected. I felt dejected—I felt rejected. I felt my heart cut open—I felt cut off from my "friends"—my colleagues.

For months I was shattered, feeling unfairly wronged. People at work who knew me only on a business casual basis stared sharing rumours about me and my circumstances—some were even so bold as to ask me about my "stress level" and "coping skills". I was told that I was sympathized with. I was told that "my situation was understood". I was told stories about other people's dealings with work-related stress. I felt humiliated that people were talking about me—judging me, and feeling pity for me. I felt exposed—naked in the reality of emptiness and isolation. Included from the internet, Figure 11, "Underwater fine art" by Ilse Moore (n.d.), is a photograph of a woman underwater. The woman's back is arched, her face is concealed, her legs are dangling beneath her body which is scarfed in crimson ribbons. Body that is cut off from its heart, this photograph embodies my felt existence—naked in the reality of emptiness and loneliness.

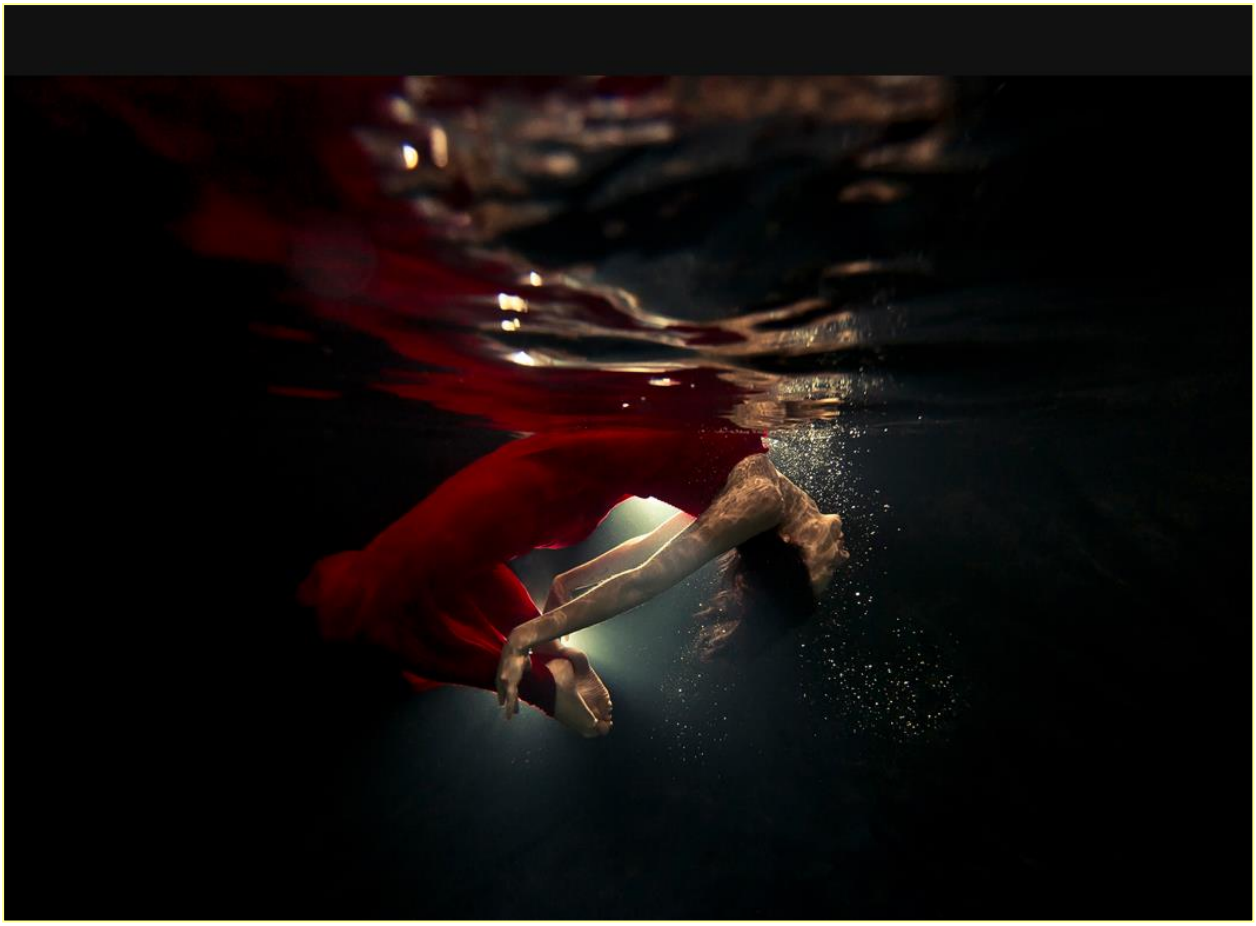

Figure 11. "Underwater fine art" by Ilse Moore (n.d.). Body that is cut off from its heart, this photograph embodies my felt existence—naked in the reality of emptiness and loneliness.

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Act 5: Resolution

As much as I would like to conclude my story as the protagonist who is better off than at the story's start, my memoir, in part, follows along the lines of a tragedy. Through crisis—through illness and disability—I was forced to experience identity change and hence transform my learning—my thinking—about myself and my relationships with others.

Within my own brokenness, I was ashamed of who I was. I felt ashamed for hating that part of myself that defined me—the part of myself I kept hidden. With words, I lashed out at my parents, husband, and children. I was angry at society. I felt that I was allowed to participate in life only if caged by medication—straight-jacked by the norms of society and my workplace status quo.

And then … I discovered L'Arche and I learned how to regain my voice through writing.

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Jules.

Jules and I entered each other's lives at a time when we were both struggling. She—trying to overcome feelings of grief and loneliness after the death of her father, and I—recovering from illness and depression, trying to unlock myself from the emotional hopelessness and helplessness of my changed identity.

From the first moment I met Jules, I knew that she was a very special person. Through her gentle tone of voice and quiet mannerism, Jules made

apparent the blessing of her sensitivity—both of herself and for others.

Although we shared greetings during L'Arche Community events, we started to spend time together after I discovered that Jules was going through a sad and difficult time. Since I knew, too well, the piercing pain of depression, instantly I was drawn to Jules. I felt we might relate well with each other, having shared similar struggles. Perhaps because I felt that I couldn't help myself, I wanted to help Jules feel comfort and happiness.

Over the 12-months, each Monday afternoon, the two of us would meet. We went for walks with my dog, took trips to the library, visited my parents, went shopping, or ran errands. Jules was always pleasant and content to partake in whatever weekly activity I had planned. We talked, over a mug of coffee or a glass of chocolate milk, about things that were happening in and important to our lives. Jules proudly shared with me her journal: a collection of crayon illustrations, cut-and-paste photographs, scribbles from scripture passages and prayers and note—thoughts—about things that were happening in her life. I shared information about myself, my family, my studies, and my jobs.

I was always cheerful—but careful not to share any part of myself that wasn't "happy". I didn't want Jules to know the side of me that felt lost and ashamed. I didn't want Jules to pity me or feel awkward around me because of my weakness. In hindsight, I realize now that I felt embarrassed about my own failure to overcome depression; I felt scared to let anyone, including Jules, see my vulnerability.

Then one evening, during Community Prayer Night, Jules taught me that it was O.K. to be hurt—and it was O.K. to be vulnerable.

It was customary, during Community Prayer Night, for core members, assistants, volunteers, and friends from L'Arche to meet in one of the community homes for a quiet time of worship and reflection. Everyone squeezes into a large open room lined with simple wood benches and handmade pillows. People position themselves comfortably in a circle while remembrance candles are lit. Jules sometimes assisted the Community Coordinator by reading prayers. One night while Jules led the Community in prayer, I remember—quite distinctly—her unassuming yet powerful participation; that particular service moved me to tears. Jules was so honest, so open, and so prevailing.

Jules's voice was soft and kind; she spoke about love and forgiveness—for herself and for others who had hurt her.

Jules's presence was peaceful; in the circle she sat quietly. Her hands folded under her chin, her head bowed low. Her posture bore the innocence of a praying child, yet it also conveyed the felt existence of a weathered cleric.

Jules's gestures were gentle; her eyes were forgiving. Small tears trickled down the side of her check and dropped to the ground. Raw emotions of pain, suffering, faith, and joy were reflected in her eyes.

As I looked at the tears that seem to melt on the ground in front of us, my heart ached. I wanted to take away her pain and stop her from crying. I wanted to help her feel better. But then, Jules looked up—as if she could see

into heaven—and she smiled. She thanked God for helping her, for forgiving her, for loving her and for bringing her into His service.

The Community Prayer Circle continued—hymns were sung, people prayed for their loved ones, and the service concluded. For a few minutes thereafter, I sat in silence—feeling awestruck. Aware of my own emptiness, I longed to be closer in relationship with God—just as Jules demonstrated so completely.

By allowing her raw emotions to be seen and heard, Jules made herself vulnerable to those around her. She taught me how to connect—to God—to Mother Earth—through one another.

Vulnerable for us to her cry—and smile;

Vulnerable for us to hear in her voice pain—and forgiveness;

Vulnerable for us to feel her sorrow—and his triumph;

Vulnerable to share the beauty of being in relationship with God.

Through Jules I learned that it was O.K. to be hurt and it is O.K. to be vulnerable when in relationship with God through others. Jules taught me that although it may seem impossible to hide—from darkness, despair, weakness, and shame—it is through our vulnerability and humility that we are able to connect with others and feel God's presence. Included from the internet, Figure 12, *"*Chiaroscuro in Photography" by Igor Kraguljac (n.d.), is a photograph of a body underwater—skin pale—arms stretched open. The body dons a white robe with a crimson sash tied at the breast. The crimson sash swirls within the white robe like blood pouring over the skin. As the broken body of Christ, this photograph embodies the gentle power of God's presence.

Figure 12. "Chiaroscuro in Photography*"* by Igor Kraguljac (n.d.). As the broken body of Christ, this photograph embodies the gentle power of God's presence.

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With a son and mother who sometimes struggled to find voice, like the people I had developed relationships with at L'Arche, and in the clinics I worked in, I felt it my duty—my responsibility as both caregiver and cared-for, to help initiate change. Having been blessed with a loving and supportive family, exceptional health care providers, education, and financial resources, I felt like I was in a position to help advocate for others—whose "disabled" voices were weakened—who were experiencing situations similar to mine—of stigma and disability discrimination in the workplace. Truly, from a place of care and naivety, I wanted to help make a difference.

Each time I tried to bring my concerns forward to be heard in the hollows—the "halos"—of bureaucracy – my voice was lost. My concerns echoed in silence against what felt like a myriad of organizational processes governed by administrators who wielded bureaucratic power and control over "their" human resources—"their" commodities—rather than recognizing and supporting "their" workforce as collaborative beings in the mutual enterprise of employment. And so, after almost a year of attempting to evoke organizational change through the university's administrative channels—"neatly" defined but ineffective institutional procedures—on June 21st, 2011, exactly one year after the university deemed me unable to work full-time because of my "health conditions", I filed an application with the Human Rights Tribunal of Ontario.

Hoping for mitigation from the university—instead I received only litigation.
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Pressure and intimidation tactics were dispersed against me. My requests for evidence—meeting notes and correspondence that discussed my case, held in the university's human resources department—were denied. Knowing how important it was for me to maintain my medical privacy - the university's developed witness lists—sent to the tribunal office as part of the hearing preparation package that included almost every person I had ever worked with over a 7-year period at the university. I felt worried and embarrassed that my colleagues had been informed of my mental health illness. I tried to act strong and pretended that their tactics didn't bother me. Continually, at every step of the process, the university tried to shut me down. But I wouldn't let them; if anything, their actions only made me want to try harder. I wouldn't allow them to sweep my concerns—my experiences—under the sheepskin—the wolf skin—of bureaucratic procedures.

In my education studies, my focus had turned from organizational learning to learner-centered education in organizations. I was searching for answers—answers to questions that perhaps didn't exist. Through excerpts taken from course work and assignments, a back-and-forth process of trying to rationalize my experiences as an advocate—teacher and learner—was pronounced.

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November 7, 2011 – Excerpt from Assignment: Stigma & Fear.

I've been thinking about how fear … associated with self-stigma, has impacted my participation in various activities involving learning. As a woman living
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with a mental health disability, I am fearful of how people might react to me if they knew that I have a mental health disability. I am fearful of stigma because of my disability.

In terms of learning, I have "held back" from attempting to push myself to higher levels of education, for fear—out of a misguided belief that others have told me "I couldn't handle the stress. And now, having entered into a Master of Education program at Brock, for the first time in my life, I feel like I have regained my voice—through writing. Through writing my voice, I am able to share my abilities; I feel empowered to contribute more fully to the learning and development of myself and others.

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November 14, 2011 – Excerpt from Assignment: Voice in Community.

During preparation for class this week, an overriding theme has resonated in my thoughts … the importance of voice in community—especially the voice of those who may be vulnerable. How often do we, as those who hold power or positions of influence (as educators), stop to consider and listen to the silent voice of those less fortunate? Do we provide opportunity for the silent
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voice to be included in community participation? How do we involve the silent voice in decision making?

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For over a year I stood my ground strong – until it came time for my application to be heard at a hearing in July 2012.

In a broken frenzy, 2-weeks before the hearing, the pressure from the university's legal department started to get to me. I started to become manic—working all night on my case notes and forgetting to take my medication. Over a two week period I had lost almost 15 pounds. In one of several phone calls I received from the university's counsel, I was "warned" that the university had hired a legal expert who, at the time, was working on behalf of the Ontario government to evaluate the inner workings of Ontario's human rights systems. I couldn't believe it. I felt intimidated and disadvantaged. I felt betrayed by my government for creating a system that allowed the privileged—the university with its academic clout, old boys' networks, and financial backings—to gain intimate access to the very system that was designed to allow persons who had been marginalized because of difference, equitable access to social justice.

At this point, in my mind, my fight—my plight—evolved into something bigger than myself—something bigger than the administrative policies and processes within my workplace. What was facing me—what had become glaringly clear to me—was the underbelly of "organized" administrative chaos. Where systems of rules, regulations, political authority, and dominant cultural norms were enacted to
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"unify" people and their interactions—relationships—with one another in "civilized" society, clarity in its framework was lacking.

And so, my mission changed. I found voice in writing—I found voice in researching—I found voice in reading. Carefully, I reviewed the legislative acts that were relevant to my case, and I compared them to the organizational theories of care and justice I had learned about through my studies. Where deficiency lay, I took careful notes and began to organize my thoughts on paper. During this process, I contacted every administrative body I could think of that I thought might have influence over the system process that impacted my case and my human rights. I contacted Human Rights officials, members of provincial parliament, members of parliament, cabinet ministers, senators, members of the Upper Canada Law Society, Ontario's ombudsman. I voiced my concerns as a public member and as a person who had been marginalized by the very systems and processes intended to provide social equity.

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E-mail Sent: June 27, 2012, 04:59 AM

I am a person who has experienced mental health discrimination at my work place. I have filed an Application with the Human Rights Tribunal of Ontario – which will be heard next week. For anyone who has experienced discrimination, navigating the Ontario Human Rights system can be an overwhelming and emotional process. For persons with mental health disabilities
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> however, the experience is so much more overwhelming and difficult. This is especially true if faced with a Respondent Employer that has access to inside information about the unique vulnerabilities that persons with mental health disabilities experience in the process of discrimination and in attempting to seek resolution and justice through the Ontario Human Rights System. And so, I bring to you my concerns …

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The week following, my case was heard. I hired a disability rights lawyer to help me through the process. I needed that support, as it was difficult for me to express myself in spoken words. And so the university settled their differences with me without going to a full trial. This meant that the details of my case - my disabilities - remained protected from the public domain.

A couple weeks later, I logged onto the Ontario Human Rights Tribunal web-site where I noticed a change. Highlighted in the Tribunal Appointment Process section, a new statement had been added. It read that,

> Members of the Tribunal are appointed by the Government through an Order-in-Council from a list of candidates recommended by the Tribunal. The Tribunal develops this list by following an open, public and competitive recruitment process in accordance with the directives of the Public Appointments Secretariat and the requirements
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> in the *Code*. This list of qualified candidates is then provided to the Attorney General for consideration. ("Human Rights Tribunal of Ontario")

Seeing those words in text—somehow—within that space, place, and time, I felt vindicated. I felt that my voice had been heard. I felt that through all my painstaking efforts, I had helped make a positive change. I felt at peace.

Less than 6- months later, I fully resigned my position from the university. No longer impacted by a system of administration that had made me feel broken, I moved on.

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Living in the Skin that I Am.

Submerged underwater I see the beauty of the sparkling sunlight peeking through the surface as I look up from below.

It is like a crystal sky.

I am comforted and mesmerized by its beauty—its tranquility.

I never want to surface again.

I want to stay submerged in God's glory.

Here—in the cool waves that surround me—I am beautiful—I am free.

Surfacing only brings me closer to the painful reality of having to breathe - again.

I do not want to feel the world through my burning skin—through my aching bones—through my bleeding body and tired head.

I am alone—in this body, trudging myself—my skin, my bones, my blood, my flesh—through life.
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All of me can so easily be altered—changed—through the absent beat of a heart, in the crash of a car, through the decay of cancer.
What would I look like without skin? Without bones, blood, or flesh?
I think I would be beautiful and free like Mother Earth.

Included from the internet, Figure 13, “Underwater Bliss” by Erik Aeder (n.d.), is a photo of a woman underwater. She is wearing a white gown draped with sheer sashes of crimson and white. With body positioned upright, the woman’s arches backward so that her arms are able to embrace a whirling wave of water that pushes her up towards the surface edge. This photograph embodies my warrior salvation—rising up and above—sensing life in its completeness.

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Figure 13. "Underwater Bliss" by Erik Aeder (n.d.). This photograph embodies my warrior salvation—rising up and above—sensing life in its completeness.

And so my story continues—just as it did before—the same, but different. Like many Canadians—I continue to be a person who experiences life with invisible and episodic disabilities. I live in a changing body that lives in a rapidly changing world. Some of the changes around me and inside me, directly and indirectly impact my health. And—like all people who experience life with invisible and episodic disability—the environment I live in and work in, sometimes more significantly than other times, contributes to the changes I experience in my health—and in the way I am able to participate and contribute in society. Included from the internet, Figure 14, by Elena Kalis (n.d.), is a photograph of a woman walking underwater. As she walks along the sandy ocean bed, her head is hidden above the surface. A crimson cloth gown flows alongside her body as the sun glimmers through the water's surface. This photo embodies my concealed identity. In the skin that I am—body separate from mind—hidden within its faceless image—I am walking— waking—to a new identity in the role and purpose for which I have been created.

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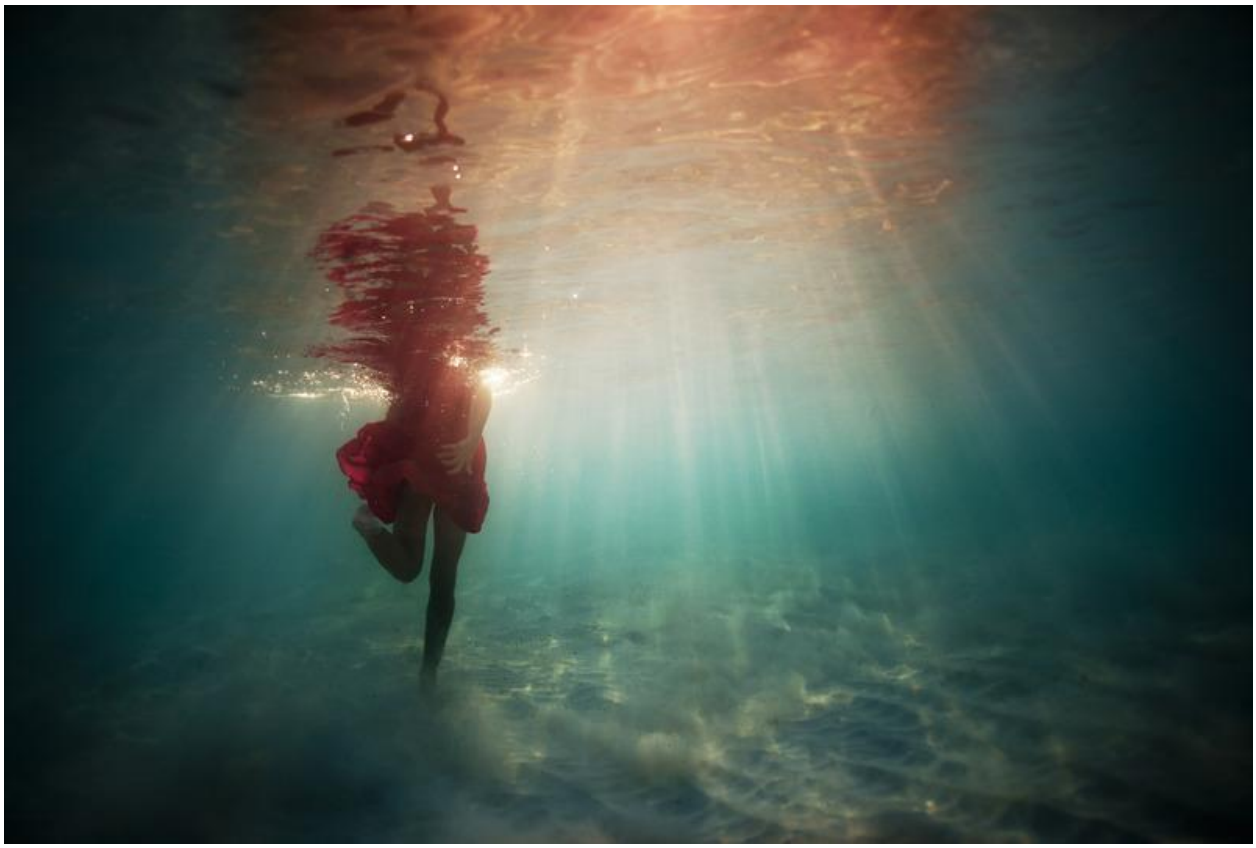

Figure 14. "Underwater_elena_kalis55.jpg" by Elena Kalis (n.d.). This photo embodies my concealed identity—walking—waking—to a new identity in the role and purpose for which I have been created**.**

CHAPTER FIVE: UNMASKING THE PANTOMINE

Story, according to Connelly and Clandinin (as cited in Clandinin, Pushor, & Orr, 2007), "is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful," (p. 22). The story about my experiences with stigma and discrimination—as both learner and teacher with invisible and episodic disabilities—makes meaning of my interactions with family, friends, and the social networks that surrounded me.

A Critic's Review

As a professional adult educator with invisible and episodic disabilities, the temporality of my story—stories within stories—is framed "before" and "after" my diagnosis of mental illness and my experiences with bleeding and stroke related to HHT. In retelling my stories, my present knowledge and insight regarding mental illness and HHT have influenced my understanding of the "before" and "after" events and their contributions to my experiences of workplace stigma and discrimination - experiences that were difficult for me to rationalize at the time of their occurrence.

Dimensions of my "storied" stories, follows the conceptual framework identified by Connelly and Clandinin (2006) of the "three commonplaces of narrative inquiry – temporality, sociality, and place" (p. 479). They also parallel Spry's (2011) metaphoric model of performative autoethnography –using body, paper, and stage. In the place and space for which my story is told, "the specific concrete, physical and topological boundaries of place or sequence of places" (Connelly & Clandinin, 2006, p. 480), the changing locations of my schools, workplace, and home are revealed. As

my stories unfold, the temporality of the stories' events evolve and my lived experiences become a reflection of organizational sensemaking surrounding me.

My story of identity change

In the stories, *My Concealed Identity*, *Bleeding from the Outside in, Blood Line #1*, and *Blood Line #2*, I write about the heritage of my body's secret identity—broken and disconnected in mind and spirit. Chilling poetry that describes the fear of living in the skin that I am becomes the stage from which my body is described in experience. Language of imagery in the depiction of a woman underwater—unmoving—mind disconnected from body—a faceless image is used in the process and product of embodied writing—body—paper—stage—the felt performance of body is echoed. Spry (2011) makes reference to this type of methodological process, where

> analysis, composition, and performance are deemed interdependent through the concept of *textualizing body* where no epistemological hierarchy exists between page, stage, word, or body; the body/self, the autoethnographic text, and the performance of the text contribute equally to the meaning making process … [where] performance is not an added scholarly bonus … [it] does not "illuminate" the text, rather it assists in the creation of the text, and it is itself performative. (pp. 28—29)

Spry described how the body is tantamount in autoethnographical work – especially in the experience of loss and healing. Specifically, she states, "it is the presence and absence of bodies that constitute the experiential evidence of loss" (p. 20). In loss of

myself—in recognition of my different self, in writing the story of my concealed identity—I took the first step towards healing.

Right from an early age, school and learning were important for me; it created the space from which I could escape the reality of my feelings; it allowed me to get lost in a sea of distraction by exploring something new—losing myself in thought and attempting to find answers to the puzzles that filled my head. As I grew older, my love for learning expanded. I sought refuge in the halls of the university where I could lose myself in other people's thoughts through the pages of the books and journal articles I read. Through the course of my experiences in school and in work, I can trace the physical and emotional "ups" and "downs" of my abilities and disabilities. Clandinin, Pushor, and Orr (2007) recognized the temporality of events in transition—just as my interpretations of events transition across my life—when they stated that it is, "important to always try to understand people, places, and events as is process, as always in transition," (p. 23). From the commonplace of sociality, *The Pit* is a story where my feelings, reactions, and moral disposition are described in detail. The portrait of a happy child who loved to learn and be in school was contrasted against the description of a child who was sad, solemn, lonely and ashamed. The social conditions of this story that include the "existential conditions, the environment, surrounding factors and forces," (Connelly et al., 2006, p. 480) relate mostly to the lack of awareness that existed during that time amongst my teachers and parents regarding the signs and symptoms of early onset—childhood—mental illness. Had my parents and teachers recognized the severity of my mood

changes as a sign of mental illness—my withdrawal from activities and friends—I wonder how much my life and learning would have changed? Would I have had the same opportunities to attend the same schools as "normal" children? Would I have been able to grow into the self-directed learner I am today?

Zimmerman (2002) described the process of independent – self-regulated learning that is

> not a mental ability or an academic performance skill; rather it is the self-directive process by which learners transform their mental abilities into academic skills. Learning is viewed as an activity that students do for themselves in a *proactive* way rather than as a covert event that happens to them in reaction to teaching. (p. 65)

From passivity to activity, resilience and freedom of spirit, the poem *I Am a Nighthawk* embodies the presence of "being" in the moment—in the cloaked shadows of nighttime—alone and connected to the silent world surrounding me. In solitude, restless and relentless, a learning identity of presence takes transformation in the struggle to find words that makes sense of an embodied experience. Like a bird that spreads its wings high in the sky—free to soar—an embodied presence of "being" in the moment is free to explore.

In a similar vein that *I Am a Nighthawk* moves my learning identity from a place of passivity to one of activity, *Memoirs from a Happy Time* takes a reverse approach. In a collection of students' notes, a story of reminiscence, sharing, and mutuality is told. Uncovered in this story, learning has taken shape in a process

where both teacher and learners take risk, that challenges their underlying assumptions about what it is to teach and what it is to learn. Askeland (2006) described this experience of critical reflection by stating,

> Critical reflection implies taking risks, making ourselves vulnerable by throwing off masks we use in encounters with others. It means opening up to hear, see and put words to what we may protect ourselves against. By sharing my experience with the students and a colleague, I took the risk of being regarded as incompetent. (p. 109)

Shifting back and forth between the roles of teacher and leaner, caregiver and cared-for, the stories of *Survival*, *Trapped Inside My body*, and *Gripping the Wheel* expose the heartbleed of my vulnerability in the face of physical and emotional identity change. Offering insight into the experiences of loss and loss of self through embodied writing, these sensemaking stories are critical to my learning transformation. Raw emotions—through words—overwhelm me. As told through the framework of "temporality, sociality, and place," (Clandinin & et al., 2006, p. 479), the story of *Survival* surrounds my struggle and diagnosis with mental illness. It was a time of great darkness in my life—a time when I was forced to redefine my identity—as a "patient"—as a person with mental illness. When writing *Survival*, I was forced to think about the critical events that caused me to acknowledge the severity of my mental illness and accept my doctor's diagnosis. It wasn't until words helped shape meaning for those painful memories—buried deep—shelved at the back of my mind—that I was able to fully appreciate the role that my husband played

during my pregnancy and in keeping me alive and safe. As I reread the words, "*I had cut myself off from my friends and family—al l except my husband. He stayed by my side and took care of me,"* I feel my husband's love for me revealed through narrative.

Like *Survival*, *Trapped Inside My Body*, and *Gripping the Wheel*, are stories positioned on a continuum, where "experiences grow out of other experiences, and experiences lead to further experiences … ----the imagined now, some imagined past, or some imagined future—each point has a past experiential base and leads to an experiential future" (Connelly & Clandinin as cited in Clandinin, 2006, p. 46). Strong in these stories are the experience of my personal condition—my body changed.

In *The Voice of an Emerging Advocate*, and *My Evolving Identity*, my body changed; my forced identity change in the experience of crisis echoes loud. These self-reflective stories serve both as process and product in the sensemaking experiences of stigma and discrimination. As Weick (1988) described,

> Sensemaking in crisis conditions is made more difficult because action that is instrumental to understanding the crisis often intensifies the crisis. This dilemma is interpreted from the perspective that people enact the environments which constrain them. It is argued that commitment, capacity, and expectations affect sensemaking during crisis and the severity of the crisis itself. It is proposed that the core concepts of enactment may comprise an ideology that reduces the likelihood of crisis. (p. 305)

Literary reverence through embodiment

By engaging the body in the sensory act of piercing feelings into text through the use of lyrical imagery and visual language, my abled and disabled body is able to evoke literary reverence in the sensemaking process and lived experience of stigma and disability discrimination within a workplace culture of organizational administrivia. Words used as poetry, text written in prose, and images that evoke the sensitivity of a disability experience—struggling to stay afloat against the drowning waves of bureaucracy. In expressing the body's felt brokenness—in self and through others—the vulnerability of self and the body's held knowledge surfaces as raw emotion, intuition, and instinct. This surfaced embodied knowing fuels the source of empathetic connection between self and others as new knowledge is constructed and reconstructed in the process of critical reflection. In the reconstruction of my experiences with illness, disability, stigma, and discrimination through story, waves of memories, feelings, emotions, and thoughts surfaced within me and swirled around me. Dispersed throughout the narrative text, images—photographs of women underwater—play a key role in the performance my story. Where words felt feeble to evoke the experience of body—the body's experience is impressed through image.

Through the use of simple prose, the uncertainty of experience—of reality and "sur-reality" is fleshed out in the stories of *Lost in Thought* and *Filling in the Gaps.* Through embodied writing, the felt tension of managing reaction—stigma—in the face of disability disclosure is capitulated. Goffman (as cited in Beatty & Kirby,

2006) summarized the impediments of managing an invisible stigmatized identity by stating,

> The issue is not of managing tension generated during social contacts, but rather that of managing information about his [the stigmatized individual] failing. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where.

Not knowing how to manage—not knowing how to communicate the failings of my changed body—in the face of bureaucracy—I became paralyzed. My body was lost in thought and my mind unable to fill in the gaps.

My role as an educator through the paradigm of disability

Moving through the paradigm of disability, my role as an adult educator has been shaped by the experience of identity change and Other-relatedness. Shifting through identity change—from teacher to learner and learner to teacher—from caregiver to cared-for and cared-for to caregiver—I have gained "new" insight into the mutuality of learning and being in relationship; it has ignited my understanding of the temporality of transformative learning.

In the stories of *Jules*, *My Mentor My Tormentor*, and *Living in the Skin that I Am*—tribute stories about the power of vulnerability in a shared existence—words felt scarce in their delivery. Spry (2011) acknowledges this aspect of autoethnographic performance – where words see to fall short – by stating that

> words may fall about us we may sometimes lurch within the boundaries of performance only to stumble upon a shard of language telling the messy

> beauty of being with others; old grammars of fear may fracture under the weight of oppression leveled upon us – or that we have leveled upon others. The process of writing and performing critical autoethnography, or performative autoethnography as it will be conceptualized here is the continuous negotiation of account for who we are with others in culture on page and stage and back again. (p. 27)

When I wrote *Jules*, words flooded me—thoughts and feelings of being in relationship with others through brokenness. I imagined the feeling of a broken human body as a condition in which,

> *Nakedness exposes the reality of*
> *emptiness, anguish, loneliness,*
>
> *and the feeling of death.*
> *And out of this experience*
>
> *comes both a closing in, a fleeing from reality* (Vanier, 1988, pp. 22-23).

Through these embodied words, humanity's brokenness is related to a body that is cut off from its heart—one that is naked in the reality of emptiness and the feeling of death—a felt body that is disconnected between spirit and mind. Induced are sensations of fear, shame, and despair. When I wrote *Jules*, my body was broken and vulnerable. When I wrote *My Mentor My Tormentor*, I wrote about myself—what I perceived others to see in me—as reflected through another. In learning to adapt to my disability experiences, by "resolving the tension between body and self … [and] defining integration and wholeness of being while experiencing loss and

suffering … living with illness without living solely for it" (Charmaz, 1995, p. 658), I wrote *Living in the Skin that I Am*. It serves as a life requiem—a poem about a felt existence outside my body.

Epilogue

In bringing closure to my autoethnographic experience of ability and disability, stigma, and discrimination as an adult educator working against the backdrop of organizational administrivia, I am reminded of one last story. A story about my niece and what it means to free-colour.

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Free-colouring

At the dinner table, my 5-year old niece, Rachel, shimmers like the Christmas tree that stands behind her—adorned with red-hot lipstick and baby-blue eye shadow, a sparkly rhinestone tiara, glitzy costume necklaces and bracelets, and a light-up Santa brooch pinned to her sequined rainbow sweater—she sits and waits. Like a princess, she waits—patiently—for the waitress to return to our table with some crayons and paper. With a clever smile, Rachel whispers to me that she is going to colour a picture for Santa. Only two days before Christmas—I can tell she's excited.

Within a couple of minutes, the waitress brings a basket of crayons and a children's menu—on the back is a picture of a snowman. She sets them on the table in front of Rachel. Carefully, Rachel survey's the colours—touching each waxy pastel with her sticky little fingers. She selects a bright purple crayon and begins to colour the snowman's hat. My brother—a seasoned
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elementary school teacher—clears his throat before informing me that Rachel has become quite skilled at colouring. “Before,” he said, “she used to scribble all over the page, but now, she colours perfectly within the lines.”

“Hmm,” I reply while gazing upon my niece’s angelic little face. “Is that true Rachel, did you scribble all over your pages?” I ask.

In her squeaky schoolgirl voice she replies ever so politely, “No, Aunt Susan. I never scribbled on my work.”

My brother is quick to respond, “Oh yes you did! Don’t you remember all those pieces of paper you brought home from school? They were covered with scribbles!”

Rachel looks up. With a mischievous little grin she clears her throat; she wants to be sure we are able to hear every word she plans to say. “Daddy, I never scribbled outside the lines. I only free-coloured outside the lines. Don’t you know what free-colouring is Daddy? It’s called art.”

Figure 9, “Colours II” by Colleen Fiddler (n.d.), is a photograph of crayons submerged underwater. This photograph embodies the freeness of colour – moving from the black and white image of a woman floating underwater – to the vibrancy of life – living and loving in colour.

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Having lived constricted in a disability paradigm and experienced stigma and disability discrimination in the context of an adult learning work environment, through education and experiences of Other-relatedness, I have come to appreciate life—in ability and disability—as one and the same on the continuum of experience. Before I ventured into the performance of autoethnography, my world felt mostly
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Figure 15. "Colours II", by Colleen Fiddler (n.d.), is a photograph of crayons submerged underwater. This photograph embodies the freeness of colour – moving from the black and white image of a woman floating underwater – to the vibrancy of life – living and loving in colour.

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black or white. I was stuck in a mindset where I felt broken—helpless because I didn't fit neatly into a box—hopeless because I had been placed in a box that I wanted to escape from. Through the interactive process of introspection, dialogue, and critical reflection, layers of the skin that I live in have been ripped open, examined, and stitched up. Through the deconstruction and reconstruction of my patchwork storied life, I am able to appreciate that voice may assume different modalities—on paper, in body, and on stage. Voice may be heard, seen, felt, and experienced. Voice may echo in silence, and voice may quietly roar. Voice may take the form of colouring neatly within the lines, or voice may appear scattered in its creation through difference—in the beauty of art.

As a teacher and learner with invisible and episodic disabilities, my narrative of transformation, in terms of how I see myself—how I see myself through others, and how I see others through me—has left me with a greater understanding about what it means to act with purpose and consideration in relationship with others. Through the brokenness of our embodied selves—with others—we may gain greater insight about what it means to be human and how it feels to be whole. Resonating in my thoughts, the words of Clark & Sharf (2007) provide succinct closure to my autoethnographical experience. They stated that

> we choose to enter the lives of others—especially those in vulnerable situations and at pivotal points of time—with intentions of both giving voice to the depth and richness of individual experience and accomplishing socially relevant changes within the contexts examined …. Our shared humanity is the ground on which we and our participants stand. It not only makes

understanding possible between us, it is the basis of our relationship together, and it is the relationship that is the heart of the matter. (pp. 399—400)

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